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ONLINE SOCIAL SUPPORT AND CANCER: UNDERSTANDING THE IMPACT OF SURVIVAL RATE, GENDER, AND DIFFERENT COMMUNITY CHARACTERISTICS

By

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ABSTRACT

ONLINE SOCIAL SUPPORT AND CANCER: UNDERSTANDING THE IMPACT OF SURVIVAL RATE, GENDER, AND DIFFERENT COMMUNITY CHARACTERISTICS

By

Lorraine R. Buis

Introduction: Social support is an important part of dealing with cancer. Traditional support groups where people connect with others experiencing similar situations have been commonly utilized for several decades. With the advent of the World Wide Web, online support communities have become a very important tool for finding social support when experiencing illness. Due to the benefits that online support communities afford, it is unsurprising that millions of people turn to online support groups to find emotional and informational support for a variety of different diseases and conditions.

Objective: This investigation sought to compare social support messages contained within eight online support communities for cancers with varying five-year relative survival rates, as well as understand how the five-year relative survival rate of specific cancers and other community characteristics such as community host, openness, post volume, and size affected the demographic makeup of community members in terms of gender and community member role, as well as social support messages. In addition, this investigation sought to test Optimal Matching Theory, a theory of social support, in this electronic realm.

Methods: A quantitative content analysis was conducted on 3,717 messages located in eight different health-related online support communities focused on four different types of cancer with high and low five-year relative survival rates. Of the eight communities located in this sample, four were hosted by Yahoo!Groups (a general-purpose web portal) and four were hosted by ACOR (a cancer-specific community host). Intercoder reliability was obtained with all variables receiving a Cohen's Kappa agreement of at least .85.

Results: Data from this investigation indicate interesting findings as significant relationships were found between types of social support messages and community member role, five-year survival rate, as well as different characteristics of the communities such as host, openness, and post volume. Although support was found for the first hypothesis indicating women will post more frequently than men and will provide a greater proportion of emotional support provisions, no support was found for hypotheses predicting that emotional support provisions would be more prevalent in communities for low survival rate cancers, while informational support provisions would be more prevalent in communities for high survival rate cancers.

Discussion: Results from this investigation point to a number of interesting conclusions that have significant prescriptive implications for the design of online support communities and web-based services. In addition, this investigation raises new and important questions to guide further research in this field.

To my father Ronald Stewart, my grandparents Stanley and Ruby Stewart, and my cousin Christopher Parka, who passed away before having the chance to see me achieve this remarkable accomplishment.

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Chapter 1: Introduction

In the year 2007, it is expected that approximately 1.4 million people will be newly diagnosed with cancer (not including basal and squamous cell skin cancers, as well as most non-invasive cancers) and that almost 560,000 Americans will die from cancer. In the U.S., cancer-related deaths account for one out of every four deaths. In fact, cancer is the second leading cause of death, only surpassed by heart disease. Although the average five-year relative survival rate for all cancers is 66%, there are some forms of cancer that have substantially higher or lower five-year relative survival rates (American Cancer Society, 2007).

Previous research has indicated that cancer can be caused by both internal and external factors. Although the risk of developing cancer increases with age, cancer can occur in anyone regardless of age, race, or gender. Overall, it is estimated that men have a slightly less than 50% lifetime risk for developing cancer, while women have a slightly higher than 33% lifetime risk. Due to its high prevalence and the fact that cancer knows no boundaries, most people will experience cancer during their lifetime, either first hand as a patient or through a family member, friend, or acquaintance (American Cancer Society, 2007).

Regardless of the average five-year relative survival rate of a specific form of cancer, any cancer diagnosis can be a scary thing. These diagnoses can be quite stressful or even traumatic. In order to help deal with the pressures associated with illness, people often turn to others for social support. Although definitions vary widely across the field, social support generally refers to "The resources provided by other persons" (Cohen & Syme, 1985, p. 4). These resources can be emotional, informational, or even instrumental. With the widespread adoption of the Internet, it is not surprising that many people turn to online avenues for social support. Between email, chat rooms, instant messaging, and listserv technology, as well as the abundant proliferation of the use of social networking sites such as Myspace and Facebook, computer users are becoming more savvy and comfortable connecting with others online. Furthermore, Internet penetration in the US has been increasing over the years and approximately 73% of adults are now online, joining the almost 90% of children ages 12 – 17. In addition, US broadband access is now available in the homes of approximately 42% of Americans (Madden, 2006). As the number of Internet users increases, along with the availability of broadband access within the home, it is reasonable to assume that more people will be turning to online sources of social support.

There are countless reasons why people may seek social support in online settings. Online support communities may be used to supplement traditional offline methods of support, or it is possible that due to any number of causes, online venues may be the only access of social support available to certain individuals. In addition to the many people that actively participate in online support communities, even more individuals lurk within these online spaces and passively participate by reading archived messages. While those lurking may not be directly participating in a social support exchange, support may still be received in the form of information, or the understanding that others are experiencing similar stressful situations. Regardless of the reason for turning to the Internet for social support, because of the widespread availability of these online communities, and due to number of people potentially either actively or passively participating, it is imperative that we begin to understand more about the types of social support interactions occurring within this electronic environment.

Despite the fact that there are numerous case studies that have investigated various types of online health-related support communities, overall, the literature in this field of study remains relatively weak due to a lack of generalizability of research findings. Much of the work in this field that has attempted to understand what types of interactions are occurring within online support communities has been focused primarily on case studies of individual communities for various diseases and conditions (Dunham et al., 1998; Klemm, Reppert, & Visich, 1998; Lasker, Sogolow, & Sharim, 2005; Mendelson, 2003; Perron, 2002; White & Dorman, 2000). In addition, a recent investigation of online breast cancer communities indicated that prior research in this area centered primarily on individual communities and this was cited as one of the problems associated with previous research in the field of online community research (Barnett & Hwang, 2006). As little empirical work has been done in the past to make comparisons across different health-related online social support groups, it is imperative that these cross-community comparisons be conducted. Not only are these comparisons essential in determining the different types of support interactions that occur online, but until we can establish cross-community comparisons, the generalizability of the online community research done in this field is minimal, as we are unable to make generalizations about a larger population from individual case studies.

This study seeks to explore the different forms of emotional and informational support that people provide to one another during situations involving cancers with varying five-year relative survival rates. Through quantitative content analysis, this investigation identifies the frequency of emotional and informational support provisions that appear within eight online support communities focused on different forms of cancer. This investigation also identifies several subtypes of emotional and informational support that are found within online support communities. As we are unable to determine individual's perceptions of social support that is received, this investigation focuses solely on the provision of social support. Focusing on social support provisions in online communities is important because as previously mentioned, there are many individuals who read through archived postings, but do not actively participate in posting themselves. It is possible that these lurkers obtain social support through passive involvement in the community through the reading of message postings that were originally intended for other individuals. In addition, this investigation also seeks to understand how factors such as the gender and role of community members, the survival rate of cancer, and other community characteristics impacts the types and amounts of social support that is provided within an online support group.

In order to guide this investigation, this study utilizes Optimal Matching Theory, a matching theory of social support, as a theoretical framework for understanding social support interactions in the online realm. Despite the fact that research in this field has yielded few strong theoretical approaches for social support research, Optimal Matching Theory provides a suitable framework for understanding the different types of online support interactions because it is not dependent on an offline context. While the problems within the field of social support are by no means close to being solved, it is essential that we begin to understand social support in pragmatic ways, in this case, within an online environment.

This research contributes to the existing body of knowledge in that it is one of the first cross community comparisons of online health-related social support communities, not only between different types of illnesses, but between different community hosts. In addition, this serves as one of the first investigations to look at the impact that community member role has on participation and social support provision in online communities. Finally, this investigation adds to the existing Optimal Matching Theory by demonstrating its use in a new, digital realm, as well finding new factors that potentially influence the discovery of "optimal matches" and more concretely determines the types of support that are best matched to different circumstances.

Although looking strictly at online social support interactions found in archived messages may only capture a slice of the total social support interactions people engage in, due to the fact that online sources of social support may potentially be the only source of support for some individuals, it is important to understand these interactions in isolation. Through looking at online instances of social support, we will be able to better understand the different support needs of people, particularly in this digital medium. From this, it is possible that we may be able to design better support services, both online and offline, in the long run.

In the next section, chapter two, a discussion of the relevant literature associated with this project is presented, followed by a series of research questions and hypotheses that were developed to guide this investigation. Chapter three provides an account of the methodology utilized in this study while chapter four presents the results of this investigation. Finally, chapter five concludes this work with a discussion of the results and their implications, as well as an identification of the limitations of this study and a description of future work needed in this field.

Chapter 2: Literature Review and Theoretical Framework

To begin this literature review, literature focused on the use of online sources for general health and cancer information is presented, followed by a discussion of online communities and the ethical considerations related to their study. Next, this chapter turns to social support; definitions, theories, impacts on health, and sources of social support. Finally, literature related to online social support is presented.

The Internet

Over the course of the last 15 years, the Internet and the World Wide Web have become a pervasive part of our society's infoscape. According to the Pew Internet & American Life project, Internet penetration has now reached approximately 73% in the US and broadband access is available within an estimated 42% of homes (Madden, 2006). In addition, statistics indicate that more and more individuals from traditionally underrepresented demographics are also utilizing the Internet as 53% of adults with yearly incomes less than $30,000 per year and 40% of adults with less than a high school education report using the Internet (Madden, 2006). Due to the fact that an overwhelming majority of our population is online, including individuals from demographic groups thought not to have pervasive access to the Internet, it is essential that we more thoroughly investigate the types of online pursuits that people are engaging in.

Health Information and the Internet

In the last decade, there have been numerous studies that have demonstrated that the Internet is a major source of health information. A recent report from the Pew Internet & American Life project has indicated that 80% of adult American Internet users (113 million people) have used the Internet to search for at least one of 17 identified health topics (Fox, 2006). The Internet is a valuable tool for health-related information due to greater access to information, increased privacy, and many other reasons (Ziebland et al., 2004). Estimates state that as many as 10,000 health-related websites are being searched (Fox & Rainie, 2000) and every day across the globe, over 12.5 million health-related searches are conducted (Eysenbach, 2003). This makes up approximately 4.5% of all conducted Internet searches (Eysenbach & Kohler, 2004).

Cancer Information and the Internet

The Internet has become a major mode of dissemination for cancer-related information. Results from the 2002 – 2003 Health Information National Trends Survey (HINTS) survey indicated that when looking for cancer-related information, the Internet was the first information source accessed by approximately 50% of American adults who use the Internet (Hesse et al., 2005). Regarding the use of the Internet for cancer-related information, particularly for breast cancer patients, accessing online medical information on the Internet has been linked to positive health outcomes (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002). In addition, there are so many sources of cancer-related information on the Internet that there are several academic articles devoted to highlighting some of the more popular and prominent resources (Junghans, Sevin, Ionin, & Seifried, 2004; Santoro, 2003).

In a recent investigation aimed at understanding cancer patients' attitudes about the Internet, it was discovered that participants were keen on obtaining cancer information from online sources, but were skeptical of unfamiliar sources that provided information. When obtaining information from reputable online sources, participants reported trust in the source and felt that they could adequately evaluate the information. When looking for health-related content, Medscape and WebMD were cited by cancer patients most frequently as their favorite websites to access. In addition, it was discovered that favorite websites listed by participants tended to be affiliated with large-scale organizations and government agencies such as the National Cancer Institute and the American Cancer Society (LaCoursiere, Knobf, & McCorkle, 2005). Furthermore, research on the use of the Internet by patients with melanoma revealed that of those participants who obtained information online related to melanoma, 94% indicated that the information was useful, 67% reported that the information helped them to understand their condition, and 45% stated that they would recommend the Internet to others who were looking for medical information (Sabel et al., 2005). Finally, it has been suggested that cancer patients utilize the Internet for cancer information through all stages of illness, specifically before visiting the doctor, during investigations, after diagnosis, during the treatment selection stage, before treatment, and for short and long term follow up (Ziebland et al., 2004).

The fact that the Internet is one of the premier destinations for medical information doesn't necessarily ensure the quality of the information. One of the inherent problems with online medical information is the possibility that there is a plethora of inaccurate information available (Matthews, Camacho, Mills, & Dimsdale, 2003). The Internet is an unregulated repository of information and at times, the quality of information available may be suspect. As such, investigations aimed at determining the quality of online information for a variety of health topics have occurred over the last decade (Impicciatore, Pandolfini, Casella, & Bonati, 1997; Kunst, Groot, Latthe, Latthe, & Kahn, 2002; Meric et al., 2002; Sutherland, Wildemuth, Campbell, & Haines, 2005).

A recent investigation of scoliosis information on the Internet by Mathur et al. (2005) found that like other similar investigations of different medical conditions, the overall quality of scoliosis information was poor and the authors suggested that "the problem that both patients and physicians encounter is not a lack of information but rather an overload of information. The valid and valuable information perhaps obscured by irrelevant and misleading information" (pg. 2,698). The notion that there is poor quality information online and that the overall quality of online information is highly variable is echoed by several other investigations (Bremner, Quinn, Quinn, & Veledar, 2006; Butler & Foster, 2003; Greene, Appel, Reinert, & Palumbo, 2005; Croft & Peterson, 2002; Hanif et al., 2006; Hargrave, Hargrave, & Bouffet, 2006; Ilic, Risbridger, & Green, 2004; Liu & Liu, 2006; Maloney, Ilic, & Green, 2005; Selman, Prakash, & Khan, 2006; Tiller, Rea, Silla, & Wood, 2006). In fact, a large review of studies focused on determining the accuracy of medical information on the Internet found that out of the 79 studies that met inclusion criteria, 70% concluded that the accuracy of medical information on the Internet is compromised, 21.5% were neutral, and only 9% found the accuracy of information to be acceptable, although the authors reported that in these instances, none of the studies used evidence-based guidelines as a standard criteria (Eysenbach, Powell, Kuss, & Sa, 2002). Recently, there have been many investigations in the literature indicating a need to establish criteria, control, and evaluation measures to help identify accurate health information and reputable sources through evaluation tools, labeling, or other forms of credentialing (Bernstam, Shelton, Walji, & Meric-Bernstam, 2005; Commission of the European Communities Brussels, 2002; Griffiths & Christensen, 2005; Griffiths, Tang, Hawking, & Christensen, 2005; Mayer et al., 2006). Despite this trend toward making it easier for health information consumers to identify reputable and accurate websites, the current infoscape is still unregulated. Although the general consensus among experts is that the quality of online health information is not always exceptional, it is essential that we focus some of our energies on moving past this to understand how the Internet is being used by people for enterprises other than seeking out information. One use of the Internet that goes beyond searching static websites for information is participating in online communities.

Online Communities

Aside from the informational benefits of the Internet, people use the Internet for many different social enterprises. One such way that people engage in social behaviors is through participation in online communities. In this next section, the definition of an online community is presented along with a discussion of how they are used for health-related purposes. Finally, the ethical concerns of researching online communities are illustrated.

Online Communities Defined

Over the course of the last decade, the notion of community has been studied from a variety of different academic perspectives. As communities have been studied across multiple social science disciplines, it comes as no surprise that the definition of community varies widely (Hamman, 2001). In the mid-1950's, Hillery (1955) attempted to understand what common themes were central to different definitions of community. Through the comparison of 94 sociological definitions, Hillery found only one common thread; they all involve people. According to the *Encyclopedia of Community: From the Village to the Virtual World*, "the lesson here is that absolute definitions are not necessary; it may be the fluidity of a core concept that makes it so useful. Community may be thought of as a geographic place, shared hobbies or interests, a warm sense of togetherness, interaction in a common space such as a chat room, and so forth." (Christensen & Levinson, 2003, p. xxxvii).

With the widespread penetration of the World Wide Web over the last decade, the notion of what is considered to be a community has been constantly challenged. As more and more people turn to the online realm for social matters, scholars are forced to acknowledge that communities do not necessarily have to be geographically bound and it is now commonly recognized that groups of people can interact with one another in virtual or online communities that reside within the Internet. The term "virtual community" was coined by Howard Rheingold (1993) in his book *The Virtual Community: Homesteading on the Electronic Frontier*. When describing virtual communities, Rheingold stated that:

> "*People in virtual communities use words on screens to exchange pleasantries and argue, engage in intellectual discourse, conduct commerce, exchange knowledge, share emotional support, make plans, brainstorm, gossip, feud, fall in love, find friends and lose them, play games, flirt, create a little high art and a lot of idle talk. People in virtual communities do just about everything people do in real life, but we leave our bodies behind. You can't kiss anybody and nobody can punch you in the nose, but a lot can happen within those boundaries*" (Rheingold, 1993, pp. 3).

To define virtual communities, Rheingold stated that they are "social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace" (Rheingold, 1993, pg. 5). Despite the fact that these words were written over a decade ago, coupled with the fact that there are many different ways that online communities have been defined, the spirit of Rheingold's definition of virtual community still rings true today.

According to the literature, there are many different ways in which online communities have been defined and studied. In her book *Online Communities: Designing Usability, Supporting Sociability*, Jenny Preece (2000) outlines several different perspectives that can be used to frame an understanding of what an online community is. The sociological perspective relies on the many decades of research based on traditional communities within the field of sociology. Scholars from this perspective tend to approach online communities as they would any traditional community. The technology perspective approaches online communities from a very techno-centric standpoint and tries to understand them according to the type of technology that is used (i.e. chat rooms, bulletin boards, listserv, etc.). This perspective tends to rely more on technologies used than on actual social interactions and organization. The virtual worlds' perspective views online communities as an immersive experience. This perspective tends to focus on the use of technologies such as MUDs and MOOs. Finally, the eCommerce perspective holds a very wide view of online communities. Rather than believing that online communities are dependent on a specific type of technology, the eCommerce perspective is more concerned with what keeps people within a site (aka stickiness).

Practically speaking, online communities in our current infoscape may appear as any combination of listservs, newsgroups, bulletin boards, message boards, chat groups, instant message systems, or web based portals where people connect with one another virtually. With that being said, the presence of these technologies does not necessarily indicate that an online community exists. When surveying different definitions of community, several common elements are found among them including the notion of membership, relationships between members, commitment and reciprocity, shared values, collective goods, and duration (Nonnecke & Preece, 2003). Without the presence of some of these characteristics, an online space is not necessarily an online community. For example, a bulletin board that was created for the purpose of exchanging information related to a specific topic may not necessarily be an online community if there are no reciprocal exchanges between members of the community. Furthermore, an online community that is filled with predominantly spam and very little applicable content may not be considered a community either.

Over the last few decades, it has been suggested that membership and participation in traditional communities, as we know them, has been decreasing. Wellman & Gulia (1999) argue in rebuttal that these traditional communities are not disappearing, rather, participation in them is taking new forms. Many researchers have suggested that participation in online communities lures people away from participating in traditional, offline communities, although evidence has yet to prove this. In contrast, many others have suggested that online and offline communities are interconnected (Nip, 2004). In a study that attempted to distinguish the differences between a traditional community and its online counterpart, it was found that the online and offline version of the same community had different norms and goals (Nip, 2004). Despite this difference, participation in online communities can increase the sense of belonging to the offline community, which can lead to increases in offline community participation (Nip, 2004).

Health-Related Communities

Of all of the different types of virtual communities, it seems that health-focused communities are among the most interesting to study at this point in time. As of March, 2007, over 37,000 electronic support groups, over 10,000 electronic fitness and nutrition groups, and over 2,700 electronic drug and medication groups had been listed by Yahoo!Groups under the "health and wellness" category. Recent estimates state that approximately 100 million Internet users are members of online communities (Rainie & Horrigan, 2005). Due to the prevalence of online health-related information and support groups, investigation of this topic is a necessity.

In the past, online communities have been studied through a variety of methods including (but not limited to) ethnography, online surveys, focus groups, and content analysis. Research has been conducted on a number of different online support communities that focus on many different health-related topics including Alzheimer's disease (White & Dorman, 2000), depression (Houston, Cooper, & Ford, 2002; Powell, McCarthy, & Eysenbach, 2003), cancer (Till, 2003; Ziebland et al., 2004), dementia (Glueckauf, Ketterson, Loomis, & Dages, 2004), and stroke (Pierce, Steiner, & Govoni, 2002), among several others. While most of the research conducted has been largely exploratory in nature, there have been a limited number of studies that have attempted to tie online support community use to health outcomes.

Despite the positive rhetoric that online support communities have received, current research suggests that we may not yet have reason to be so optimistic. A meta-analysis conducted by Eysenbach, Powell, Englesakis, Rizo, & Stern (2004) investigated the effects of online peer-to-peer interactions within online health communities and support groups. This meta-analysis found that while there was no evidence of negative health outcomes, there was no evidence of positive health outcomes either. The lack of measurable health benefits could be due to the fact that the majority of research conducted in this area has been exploratory. What has attempted to be descriptive in nature tends to suffer from poor experimental design and too few participants. In addition, in cases where statistically significant effects on health outcomes had been assessed, no information was provided as to whether these effects were clinically significant.

While exploratory case studies investigating online community use of disease-specific communities are plentiful in the literature, it is impossible to make any broad generalizations across online communities. Coupled with the fact that most of the research that has tied online community use to health outcomes may have been flawed in the research design or statistical analysis, it is essential that more deep and rigorous investigations of online support communities be conducted.

Unfortunately, some research has highlighted instances where online information and participation in online communities can have negative consequences, such as in the case of websites and online support communities for topics focused on harmful behaviors such as suicide, anorexia, and cutting and self mutilation. Previous anecdotal and empirical research has indicated that not only can individuals find information online instructing people how to behave in such self-injurious behavior, but online communities exist for the promotion and support of these behaviors (Abbate Daga, Gramaglia, Piero, & Fassino, 2006; Alao, Yolles, & Armenta, 1999; Berger, Lehrmann, Larson, Alverno, & Tsao, 2005; Dobson, 1999; Fox, Ward, & O'Rourke, 2005; Mulveen & Hepworth, 2006; Norris, Boydell, Pinhas, & Katzman, 2006; Prior, 2004; Tierney, 2006; Whitlock, Powers, & Eckenrode, 2006). In fact, a recent investigation of online communities focused on self-injurious behaviors found 406 online communities devoted to the topic by using the search terms “self-injury”, “self-harm”, “self-mutilation”, and “cutting” (Whitlock et al., 2006). In addition to providing information about topics such as suicide and other self-injurious behaviors, the use of specific suicide-related content on the Internet has been cited to have an influence on individuals’ decisions to commit suicide, otherwise known as cybersuicide (Rajagopal, 2004).

Ethical Concerns with Studying Online Communities

As with any research with human subjects, there is a tremendous responsibility to ensure that research is done ethically. The practice of conducting research in a computer-mediated environment greatly increases the number of ethical considerations that a researcher must ponder. Areas in which ethical dilemmas arise during the study of online communities include the obtainment of informed consent and protecting community participants from risks, malfeasance, and maintaining privacy (Flicker, Haans, & Skinner, 2004; Rhodes, Bowie, & Hergenrather, 2003).

As mentioned above, the collection of informed consent is made increasingly difficult when research is conducted in a computer-mediated environment. It is virtually impossible in large communities to obtain informed consent from all community members. To compensate for this, some schools of thought believe that if conducted properly, research that only looks at archives of posted messages does not need informed consent from posters.

To determine whether or not informed consent is required from community members, the distinction between public and private spaces should be made. Public spaces are open communities where any person can post messages and search the archives without restriction. Private spaces are closed communities where members must register with the group owner in order to join, post, and search the archive (Perron, 2002). In addition, these private spaces may include further restrictions, which place limitations on the types of activities that can occur within the community.

Eysenbach & Till (2001) describe three criteria to use when determining whether a community is to be considered public or private. First, if a subscription or other form of permission is required to join a community, it is probably considered private. Next, the number of members within a community can add to the perceived level of privateness. The larger the community, the less it is private. Lastly, community norms ultimately dictate the privateness of a community and codes of conduct and FAQs should be consulted.

In addition to ethical considerations when conducting research, there are also considerations to be made in regards to reporting results. First, care should be taken when identifying the specific community that is the focus of study. In order to protect the privacy of community members, researchers must evaluate whether or not to explicitly name the community. Second, identification of individual users by name or pseudonym should be avoided unless informed consent has been obtained. Third, the reporting of direct quotations from community members should be avoided unless informed consent has been obtained. With the use of Google and other search engines, not only is it possible to search for an individual member online, it is possible to find the original comment posted in an online community. These comments and online identities could then possibly be traced back to the source (Eysenbach & Till, 2001).

Now that we have explored online communities in-depth by defining what they are, how they are used for health-related matters, and identified the ethical concerns for the investigation and reporting of results, a review of the social support literature will now be presented.

Social Support

Social support, the idea that people give assistance to one another through emotional and tangible means during times of need, is a concept that is pervasive through the social science and medical literature. In this section, definitions of social support are presented along with a discussion of social support and its history of research, methods of measurement, theoretical approaches, influences, impacts on health, and sources.

Definition of Social Support

When conducting a search for the term "social support" in Google Scholar, a search engine designed by Google to specifically search scholarly literature such as "peer-reviewed papers, theses, books, abstracts and articles, from academic publishers, professional societies, preprint repositories, universities and other scholarly organizations" (Google, 2007), as of March, 2007, over 520,000 hits were retrieved. In addition, as of March, 2007, the same search in Pubmed, "a service of the U.S. National Library of Medicine that includes over 16 million citations from MEDLINE and other life science journals for biomedical articles back to the 1950s" (Pubmed, 2007), retrieved over 32,750 hits. This serves as a great indicator of the popularity of social support research.

Social support has come to mean many different things to many different people. For as many social support researchers as there are in the world, there are without a doubt an almost equal number of definitions. Although there is no concretely accepted definition, "social support generally refers to the perception that assistance is or could be available from significant others (perceived support), or to reports of actual transactions that typically do occur or have occurred between people in times of trouble (received support)" (Thoits, 1992, p. 57). Social support definitions have run the gamut of specificity and the topic has been as broadly defined as "the resources provided by other persons" (Cohen & Syme, 1985, p. 4) and as narrowly defined as "an interpersonal transaction involving one or more of the following: 1) emotional concern (liking, love, empathy), 2) instrumental aid (goods or services), 3) information (about the environment), or 4) appraisal (information relevant to self-evaluation)" (House, 1981, p.39). In his 2004 book *Social Support and Physical Health: Understanding the Health Consequences of Relationships*, Bert Uchino summarizes the state of social support research when he says "Social support is usually defined to include both the structures of an individual's social life (for example, group memberships or existence of familial ties) and the more explicit functions they may serve (for example, provision of useful advice or emotional support)" (Uchino, 2004, p. 9-10). Another conception of social support is that it is an interactional process in which two people interact with one another in both support giving and receiving capacities (Pearlin, 1985).

It has been suggested by researchers that due to the multifaceted nature of social support, we should abandon attempts at defining social support as a singular entity and rather focus our efforts on more precisely defining the broader constructs that make up social support (Cohen, 1992; Vaux, 1988). Because of the problems associated with the many different conceptions and definitions of social support "common use of the term social support had obscured the degree to which researchers examined fundamentally different facets of close relationships and their benefits for participants" (Goldsmith, 2004, p.12). Many researchers interested in more fully understanding social support do tend to agree that social support is generally divided into structural (social integration components) and functional (different types of support) components (Helgeson, 2003; House & Kahn, 1985; Uchino, 2004). The functional aspect of support is often further subdivided into different types of support. Adding to the confusion of defining social support, the taxonomy of support types varies by researcher (Cohen & Syme, 1985; Uchino, 2004; Vaux, 1988). Looking across different support taxonomies, different candidates for types of support include emotional, informational, companionship, belonging, validation, instrumental, tangible, motivational, appraisal, etc. To make matters more confusing, not only do different researchers use different taxonomies when describing functional support, they also may define commonly agreed upon support types in different ways.

To date, there has been little definitive agreement on how to conceptualize, define, operationalize and measure social support (Hupcey, 1998; Sarason, Sarason, & Pierce, 1990). What is largely agreed upon though is the idea that social support is a multifaceted concept (Wilcox & Vernberg, 1985). While some researchers claim that it is an umbrella term used for describing the different ways social relationships impact health and well-being (Goldsmith, 2004; Sarason, Pierce, & Sarason, 1990), others have gone so far as to state that "no single and simple definition of social support will prove adequate because social support is a metaconstruct: a higher-order theoretical construct comprised of several legitimate and distinguishable theoretical constructs" (Vaux, 1988).

Over the years, three primary approaches have been utilized when investigating social support: social network, psychological, and communicative approaches. The social network approach, perhaps the earliest method for studying social support, looked at how different characteristics of ones social network (density, size, and other factors) impacted health and well-being. Psychological approaches were concerned with how individual psychological factors such as the perception and satisfaction of support had an impact on health and well-being. Finally communication approaches view social support as exchanges that take place within a relationship. This more recent approach views support as an interactional enterprise with a support provider and a support receiver. (Burleson, Albrecht, Goldsmith, & Sarason, 1994)

History of Social Support Research

As previously demonstrated, information searches on the term "social support" literally reveal thousands of academic research studies where social support is measured as a variable. Further reading of many of these studies reveal poorly conceptualized and defined notions of the construct of social support. When looking deeper into the theoretical and conceptual work done in the field of social support, we are shown a very muddled and murky history of this well thought of, yet hardly understood concept. Through history, social support has been conceptualized, defined, measured, and analyzed in more ways than one could count. In fact, conflicting research findings within the social support field have often been attributed to the fact that no one conceptualizes, defines, measures, and analyses social support the same way (Barrera & Ainlay, 1983; Cohen & McKay, 1984; Goldsmith, 2004; Uchino, 2004; Vaux, 1988; Wilcox & Vernberg, 1985). To further stir this muddled quagmire of research, many empirical studies investigating social support interventions have been atheoretical (Helgeson & Gottlieb, 2000; Turner & Shepherd, 1999). As time has surged on the in field of social support research, the concept has continued to grow more convoluted. Almost any form of social interaction has come to be considered a form of social support (Hupcey, 1998). Despite the problems surrounding the concept of social support, there is one thing that people can agree on; while the mechanism by which social support works is largely unknown, there is something about relationships with others that can have positive effects on the health and well being of people.

Preliminary research on social support can be traced back over 100 years. Durkheim, in his landmark book *Suicide*, originally published in 1897 and translated into English in 1951, found that suicide was more prevalent in people with fewer social ties (Durkheim, 1951). In another preliminary study in social support, Thomas and Znaniecki (1920) documented the social disruption of Polish immigrants as they moved from small rural villages to large urban US Cities. Two seminal papers, published by Sidney Cobb and John Cassell in 1976, fueled the flames of what was to become an explosion of social support research.

Sydney Cobb defined social support as “information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations” (Cobb, 1976, p. 300). In his view, social support helps people to cope with different crises, as well as aid people in adapting to change. Through the course of this influential paper, Cobb cites various research studies focused on different points of the lifecycle (from birth to death) to back up claims that social support is a protective force in times of crisis. He cites research suggesting that social support has positive impacts on the frequency of low birth weight babies and the reduction in the amount of medication and time spent in the hospital for patients, etc. John Cassell, on the other hand, looked at social support from a biological perspective and considered it to be an important factor in disease etiology. Cassell proposed that social support is an important factor in a person's biological resistance to disease (Cassell, 1976).

Measuring Social Support

As evidenced previously, there are an incredible number of investigations focused on social support. While there is a whole host of ways social support has been defined in the past, there are also a myriad number of ways that social support has been measured. There currently exists a multitude of instruments designed to measure different components of social support. In addition, there are different sets of measures for structural and functional aspects of support. For example, Vaux categorizes social support instruments according to the types of things that they assess: measures of support network resources, measures of supportive behavior, support appraisals, support incidents, help seeking and support mobilization, and social participation (Vaux, 1988).

Instruments aimed at ascertaining measures of support network resources are primarily interested in measuring social networks. The term social network is used to describe the complete system of people that one is acquainted with. The strength of ties between network members can differ with some ties being quite strong (such as familial ties) and others being quite weak (such as common acquaintances). Social networks are quite important to the idea of social support for it is within this network that people turn to for support. Therefore, instruments aimed at measuring support network resources primarily attempt to investigate the characteristics of size, density, intensity, boundaries, etc. Characteristics of social networks such as size and density are thought to have an impact on the support that one can receive (Brissette, Cohen, & Seeman, 2000; Vaux, 1988). The underlying problem with these measures lies in the fact that each instrument fails to measure all different aspects of social networks. Most rely on evaluating one or two aspects such as size or density.

Those instruments that are aimed at measuring supportive behaviors do just that. They attempt to determine what types of behaviors a person has encountered that were seen as being helpful. This type of social support has often been overlooked in favor of social network analysis or perceived support approaches.

The largest category of social support measures, instruments aimed at assessing support appraisals, seeks to determine how helpful supportive behaviors are, or how satisfactory received support was seen by the recipient. Measures of support incidents seek to identify characteristics from actual occurrences of supportive behaviors. Another category of instruments, help seeking and support mobilization measures, attempt to determine differences between individuals and their help seeking beliefs and behaviors.

Finally social participation measures seek to identify the extent to which individuals participate in social endeavors within the community at large. Essentially, these are measures of social integration. Social integration is a multidimensional construct that often encompasses two different ideas. First of all, social integration is thought to include a behavioral component that refers to the amount of engagement one has in a wide range of activities and relationships. Secondly, it is also thought to include a cognitive component that refers to ones sense of community and identification with social roles (Brissette et al., 2000). Over the years, social integration has been operationalized differently along these two different conceptions. It has been measured through variables such as marital status, contact with friends, roles within a community, voluntary associations, religious participation, visits with friends and relatives, social contacts, etc. While some researchers choose to define social integration along behavioral lines, others define it along cognitive lines. Furthermore, many researchers include both behavioral and cognitive components in their definition of social integration. Due to the conflicts in defining social integration, it is difficult to compare research that has attempted to isolate this measure. Based on Vaux's work, Appendix A illustrates the different social support instruments based on they category of assessment (Vaux, 1988).

Despite the large number of social support instruments available to researchers, "there are few or no data available on the psychometric qualities of most of these measures or on their relationships to one another" (Cohen & Syme, 1985, p.4). The majority of these social support measures attempt to identify either psychological variables that ascertain perceptions of social support or descriptive measures that focus on the properties of an individuals support network. As such, of the overall set of social support literature, few investigations analyze the actual support interactions that occur between people. In addition, due to the fact that each instrument measures a different aspect of social support, it is impossible to use any instrument in isolation and still claim it is a valid measure of social support. Clearly, among all of the published studies focused on social support, many of them are centering on and measuring different things. This speaks to the fact social support probably is a multi-faceted construct. Without better instruments and without a more holistic approach to understanding social support, we will be unable to further our knowledge of social support and the mechanisms through which it operates.

Social Support Theories

Over the years, there have been two general models that have attempted to explain the mechanism through which social support impacts health and well-being. The two prevailing mechanisms are the stress-buffer and direct effects models of social support. In the stress-buffer model of social support, social support acts as a buffer that protects individuals from stressful events and conditions. In the direct effect model of social support, social support is thought to have direct effects on a persons psychological and physical health and well-being, independent of stress and coping processes (Uchino, 2004; Vaux, 1988). Most of the social support theories that have been proposed are born from one of these two research traditions. It should be noted that there is a well regarded hypothesis regarding social support models known as the matching hypothesis. This hypothesis (which generally falls under the stress-buffering model of social support) posits that different types of support are best matched to different stressors. Different support types can vary in the type of support offered, or the source where support is coming from. This hypothesis has been the foundation for some of the theories of social support. While the matching hypothesis has received mixed results, it has received a lot of attention. The following is an explanation of the more prominent theories regarding social support.

Transactional Stress and Coping Process

The Transactional Stress and Coping Process theory of social support was developed by Lazarus and Folkman in 1984. This theory posits that the way people interpret events and stressors has an impact on how stressful they are perceived. Lazarus and Folkman give consideration to the fact that different individuals placed in the same circumstance will perceive events differently, as well as experience different reactions and coping strategies. Furthermore, Lazarus and Folkman suggest that a transactional model "says that stress is neither in the environment nor in the person but a product of their interplay" (Lazarus & Folkman, 1984, p. 354). In order to interpret events, two types of support appraisals are conducted. The first appraisal, known as the primary appraisal, is used to determine whether or not a stressor is a threat. Each encounter is identified as either irrelevant (when an encounter has no bearing on the well-being of the person), benign-positive (when an encounter has a positive effect on the well-being of the person), or stressful (when an encounter is thought to have a negative effect in terms of harm/loss, threat, or challenge, on the well-being of the person). If an encounter is evaluated as being stressful during the primary appraisal, the secondary appraisal process occurs. The secondary appraisal is a complex process that determines what resources (either personal or social) are available to help a person cope, which of those processes is likely to successfully help a person cope, and the likelihood that a particular coping strategy can be employed effectively. Overall, the more negative the primary and secondary appraisal is thought to be, the more stress a person will experience (Lazarus & Folkman, 1984).

Stressor-Support Specificity Model

Developed by Cohen and McKay (1984) the stressor-support specificity model is a matching model of support where it is believed that in order to reduce stress, the appropriate method of support must be obtained. This model takes into consideration the notion that it is impossible to adequately consider the buffering process without taking into account the multifaceted nature of stressors and support systems. In this model, there are three different types of support, each of which is a different mechanism that allows personal relationships to buffer the stress that a person experiences. These three types of support include tangible (the offer of material resources), appraisal (assistance with defining a situation as less stressful), and emotional support (increasing self esteem and a sense of belonging). Cohen and McKay state that “Only the interpersonal relationships that provide the appropriate forms of support will operate as effective buffers” (p. 261). Cohen and McKay also take into consideration the fact that different stressors may be best suited to more than one type of support. (Cohen & McKay, 1984).

Optimal Matching Theory

The Optimal Matching Theory (OMT) developed by Cutrona in the early 1990’s is another matching model of social support. In this theory, five different types of support are identified: emotional, network, esteem, tangible, and informational support (Cutrona, 1990; Cutrona & Russell, 1990). Later work by Cutrona grouped the initial five types of support into the categories of action-facilitating (problem solving that includes information and tangible aid support) and nurturant support (emotional and network support) (Cutrona & Suhr, 1992).

Within Optimal Matching Theory, Cutrona also identifies four dimensions of stressors that may be best matched to different types of social support. These dimensions include desirability (referring to the nature and strength of negative emotions), controllability (extent to which a stressor can be controlled or managed), duration of consequences (length of stressor effects), and life domain (how a stressor affects a person) and were abstracted from theoretical and empirical investigations of social support taxonomies (Cutrona & Russell, 1990). These different characteristics determine what type of social support is required in order to achieve positive health outcomes. In OMT, the effectiveness of a type of support is dependent on how well it meets the demands of a specific stressor. Of the four dimensions, controllability, referring to the amount of control one perceives to have over the stressor, was cited as being the most important influence on the type of support that a person requires. For events with a perceived high level of controllability, instrumental and informational support is useful while events that are perceived to be uncontrollable require more emotional support (Cutrona, 1990; Cutrona & Russell, 1990). Cutrona and Russell (1990) characterize medical illnesses as negative, uncontrollable events and because illness is most often times perceived to be uncontrollable, in health-related circumstances, emotional support is often more beneficial. It is further suggested that illness can have effects on multiple domains of a person's life and support can be best obtained by talking with others who have had the same experiences in the same domains. While the exact matches between support needs and support types have not been hammered out, it is possible that further work in this field will rectify this problem.

Matching theories of social support have encountered problems over the years. These problems are largely due to the fact that stressors are not easily classified as controllable or uncontrollable and different types of support often overlap (Uchino, 2004). Despite the fact that matching theories have had very mixed results, they seem to make up some of the more promising theories of social support. The recognition that one type of support is not necessarily best for the same situation across people is an important conceptual improvement (Goldsmith, 2004). Irrespective of the problems that matching theories have faced, researchers still seem to favor them based on statistical modeling evidence that different types of support make up the higher order concept of social support and evidence that specific functional measures of the different types of support demonstrate that social support matters in regards to health (Uchino, 2004). Despite the fact that social support theory is still not concretely delineated, it is essential that we being to understand social support in pragmatic ways. Perhaps by investigating interactions, particularly from a functional support perspective, we will be able to more concretely structure social support theories.

Influences on Social Support

Like all other things in this world, it is difficult to understand social support if one considers it to occur within a vacuum. Like all human behavior, social support interactions are influenced by the context and environment in which they occur. By understanding some of the potential influences on social support, we may be able to better understand how it can be affected.

Perceived Support vs. Received Support

Within the social support field of research, the topic of perceived social support (as opposed to support that has been received) has gained a lot of momentum. A study by Barrera (2000) found that the perceived availability of support is more related to successful coping than support that is actually received. Previous research has shown consistently that perceived support measures have very strong associations with positive health outcomes (Blazer, 1982; Wethington & Kessler, 1986). It has also been suggested that the relationship between perceived and received support is complicated and the two concepts are not highly related (Dunkel-Schetter & Bennett, 1990; Uchino, 2004). Possible explanations for this low relationship include the fact that perceived support is a cognitive representation of support that is actually received by a person (Uchino, 2004). In terms of measuring perceived support, there are many different measures that look at different aspects of perceived support. Some measures focus on the availability of help, while others focus on satisfaction (Sarason, Sarason, & Pierce, 1994).

Gender

Previous literature has indicated that sex/gender is related to social support and has an effect on both the provision and receipt of support. It has been previously suggested that more than any other social status variable, gender is associated with many different factors (such as composition and size of social networks, amount of support that is received, level of emotional exchange within relationships) that may influence how social support is acquired and experienced (Vaux, 1985, 1988).

Previous research has found many differences between the genders and how gender relates to social support. For instance, studies have indicated that men receive the majority of their support from their spouse, whereas women receive the majority of their support from friends (Allen & Stoltenberg, 1995; Antonucci & Akiyama, 1987; Depner & Ingersoll-Dayton, 1988; Fischer, 1982; Kendler, Myers, & Prescott, 2005; Robinson, 1995; Vaux, 1985) although both men and women typically seek out individuals of the same sex for support (Cramer, Riley, & Kiger, 1991; Griffith; 1985; Soliman, 1993). Women also report receiving more social support from family members (Allen & Stoltenberg, 1995; Kendler et al., 2005).

It has also been established that women tend to have larger support networks than men (Antonucci & Akiyama, 1987; Belle, 1987; Fischer, 1982; Turner, 1994), are more involved in their social networks (Kendler et al., 2005; Rosenthal, Gesten, & Shiffman, 1986), provide social support more often than men (Belle, 1982; Fischer, 1982; Griffith, 1985; Kendler et al., 2005; Kessler, McLeod, & Wethington, 1985; Trobst, Collins, Embree, 1994), and typically report both seeking and receiving emotional support more often than men (Ashton & Fuehrer, 1993; Burda, Vaux, & Schill, 1984; Butler, Giordano, & Neren, 1985). Furthermore, previous research has also indicated that females are more likely than males to join support groups (Krizek, Roberts, Ragan, Ferrara, & Lord, 1999) and that current members of support groups are more likely to be female (Grande, Myers, & Sutton, 2006). In addition, a recent investigation of Alcoholics Anonymous (AA), a support group for alcoholics, found that although there were no significant differences between genders in their decision to receive treatment for alcoholism, females were more likely to attend AA than males (Moos, Moos, & Timko, 2006).

In an investigation by Turner (1994), it was discovered that women report more instances of perceived support, which may possibly be due to the fact that in this study (like previous findings), women reported more contact with their support network with greater emotional involvement than men. Despite the finding that women receive more support than men in this study, it was stated that women also appear to have more negative support interactions than men, possibly due to the increased contact and heightened emotional involvement.

In terms of gender differences within online support communities, Klemm, Hurst, Dearholt, & Trone (1999) conducted an investigation of social support within online breast and prostate cancer communities and discovered that in regards to gender, men were more like to seek or provide information and women were more likely to provide encouragement and support. This finding was largely echoed by Seale, Ziebland, & Charteris-Black (2006) in their keyword analysis of interviews and online support groups for cancer where it was found that in online communities for breast and prostate cancer, men were more likely to use keywords related to treatment, side effects, and diagnosis, as well as cite information from other websites. Sullivan (2003) also found similar patterns of social support provision in an investigation of online prostate and ovarian cancer communities where men provided more informational support and women were more emotion oriented. To summarize, Rosenthal, Gesten, & Shiffman (1986) indicate that sex differences in social support "appear to be connected with traditional sex role expectations that discourage men from engaging in intimate, self-disclosing relationships while encouraging emotional closeness and intimacy for women" (p. 482).

Other Influences on Social Support

Aside from the notion of perceived support and gender, the social support literature points to several other potential influences on social support. For example, it has been suggested that additional socio-demographic characteristics of support recipients such as age and race are potential influences on social support (Riley & Eckenrode, 1986). In addition, it has been suggested that if support providers and receivers appraise a situation differently, the support given may not be appraised by the recipient as being helpful (Dunkel-Schetter & Skokan, 1990).

Another potential influence on social support is the determination of support type, as well as support timing. Before providing support, an individual must recognize that support is needed by another and determine what type of support might be most helpful (Dunkel-Schetter & Bennett, 1990). It has been suggested that the timing of support is every bit as important as the type of support provided (Jacobson, 1986). It is possible that if support is given at a time when it is not expected, the support will not be appraised as being helpful and may not be appreciated (Dunkel-Schetter & Skokan, 1990).

Impact of Social Support on Health

Despite the fact that the mechanism through which social support operates is still largely unknown, in the past few decades, there have been an incredible number of research studies linking measures of social support to either mortality or health outcomes. In fact, some of the most influential studies regarding social support and health outcomes were large scale longitudinal epidemiological studies focused on all-cause mortality. Many research studies in this area were conducted thirty years ago, but still remain some of the most important work done in this field. To better understand the influences that social support has on health outcomes, we shall look at both influences on all-cause mortality, as well as disease specific influences.

Impact of Social Support on All-cause Mortality

Perhaps the most well known study investigating structural social support measures and mortality was the Alameda County study conducted by Berkman and Syme (1979). This was one of the first well controlled longitudinal studies attempting to link social support and mortality (Uchino, 2004). All-cause mortality is defined as death from a variety of causes, not one factor in particular. In 1965, a large scale survey was conducted by the Human Population Laboratory, a part of the California Department of Health. A total of 6,928 randomly selected residents of Alameda County, California, participated in this study. Berkman and Syme conducted a nine year follow-up to this initial study (1965 – 1974) looking primarily at mortality rates for those who participated. Through various methods, Berkman and Syme were able to locate 96% of the original 1965 sample. Looking at marriage, contact with friends and relatives, membership in a church, and group associations, both formal and informal, as measures of social and community ties, it was found that those people who had fewer social and community ties were more likely to have died during the nine year follow-up period. In addition, it was determined that each of the four structural social support measures predicted mortality independent of the other three. It was also found after looking at age-adjusted relative risks for people who were most isolated in comparison to those who were least isolated that men were 2.3 times more likely to have perished during the follow-up period and women were 2.8 times more likely. Finally, it was found that the link between social ties and mortality was independent of several factors taken into consideration in the initial study. These factors included self-reported physical health status, year of death, SES, and various health practices such as obesity, physical activity, smoking, alcoholic beverage consumption, etc (Berkman & Syme, 1979).

Another influential longitudinal study linking social support and mortality was the Tecumseh Community Health study by House, Robbins, and Metzner (1982), which was a partial replication and extension of the work published by

Berkman and Syme in 1979. In this study, House, Robbins, and Metzner compared data taken from portions of the Tecumseh Community Health study (originally collected from 2,754 adults aged 35 – 69 in the years 1967 – 1969) and compared it to current mortality information on the same participants. It was found that men who had reported higher levels of social relationships in the original study were significantly less likely to have died during the follow-up period when controlled for age and a variety of risk factors. Although data for women followed the same trend, the findings were not significant when controlled for age and a variety of risk factors (House et al., 1982).

In 1982, another longitudinal study linking social support and mortality was published by Dan Blazer. This study was a first of its kind due to the fact that it only focused on an elderly population. Blazer composed a sample of 331 seniors over the age of 65 in 1972 from Durham County North Carolina. These seniors were assessed on three different measures of social support: perceived support, roles and available attachments, and frequency of social interaction. Five years after the initial assessment, mortality status of the original sample was determined. Results indicated that all three measures of social support were predictors of mortality in this elderly population (Blazer, 1982).

To further establish a relationship between social support and mortality, researcher Bert Uchino, again in his book *Social Support and Physical Health: Understanding the Health Consequences of Relationships* (Uchino, 2004), conducted a review of over eighty published research articles linking social support and all-cause mortality. In his investigation, approximately 80% of the reviewed studies found that there were associations between either structural or functional measures of social support and lower all-cause mortality rates. Uchino found through his research that people who have low levels of social support have between two and three times greater risk of death than those with high levels of social support. Furthermore, he also found through reviews of social support and mental health that people who have higher levels of social support also live happier lives than those with low levels.

Although mortality research plays an important role in linking social support and health outcomes, it fails to capture finer grained information regarding the impacts of social support on health. For example, it has been suggested that mortality studies fail to help us understand where in the course of a disease social support has the most impact (Berkman, 1985).

Impact of Social Support on Condition Specific Health Outcomes

In addition to investigating all-cause mortality, Uchino also investigated whether or not social support has impacts on health outcomes for cardiovascular disease, cancer, and HIV/AIDS. In his investigation, Uchino found overwhelming evidence that both structural and functional measures of social support have positive impacts on cardiovascular mortality. Unfortunately, due to the small number of research studies linking social support to cancer or HIV/AIDS mortalities, Uchino was unable to draw any strong conclusions about the positive impacts of social support on these diseases, although he indicated that the preliminary findings were promising (Uchino, 2004).

Likewise, a similar, though smaller review of 17 articles focusing on the impacts of social support on patients with heart failure found that social support appears to be a good predictor of hospital readmissions and mortality in patients with heart failure. It was suggested in this review that emotional support probably plays an important role in this. Like other studies that have attempted to aggregate results across other published research, conflicting results of the impacts of social support on the health and well-being of patients with heart failure was found. But, like other review studies, these conflicting findings could potentially be explained by the differences in the conceptualization, operationalization, and measurement of social support (Luttik, Jaarsma, Moser, Sanderman, & Van Veldhuisen, 2005).

In addition to having impacts on heart failure, recent review investigations have found links between social support and positive health outcomes. A recent review investigation has suggested that social support may have positive impacts on weight loss interventions (Verheijden, Bakx, van Weel, Koelen, & van Staveren, 2005). Another recent review investigation has suggested that people with low levels of social support in the workplace may have increased risk for work-related musculoskeletal morbidity. In addition, there is limited evidence that people with low levels of social support in the workplace may have increased risk for musculoskeletal sickness absence, not returning to work after experiencing a musculoskeletal problem, and restricted activity (Woods, 2005). Another recent review of the effect that social support has on chronic disease management found the social support has a positive impact on the management of chronic diseases, particularly diabetes management, since investigations focusing on social support and diabetes management comprised a majority of the studies reviewed (Gallant, 2003).

Sources of Social Support

With the advent of the Internet, one thing has become clear. There are multiple places to find support. While traditional sources of social support such as immediate social networks and traditional support and self-help groups have been recognized as offering social support for years, it has only been in the last ten to fifteen years, with the rapid diffusion of the World Wide Web, that online social support has been identified.

In terms of traditional sources of offline social support, basic social ties with friends and family members are generally what we think of when we think of social support. In fact, for married people, the spouse is typically the first place that people turn to for support during a crisis (Burke & Weir, 1977). A long line of research has established that just being married has a positive impact on health. People who are married have lower rates of many diseases and conditions including heart attacks, strokes, tuberculosis, cirrhosis, and lung cancer. In addition, marriage also has positive effects on mental health (Argyle, 1992). Furthermore, it has also been suggested that friends can provide support in times of great stress (Derlega, Barbee, & Winstead, 1994).

When people cannot find the support that they need from their existing social network, people often times have a need to turn to other sources to find the support they require. These other sources may often come in the form of support or self-help groups. Support groups are groups of people that come together for the express purpose of gaining social support from one another. Support groups are a hybrid of group therapy and self-help groups and employ professionals to disseminate information, provide group-skill training, and guide group processes (Helgeson & Gottlieb, 2000). Support groups typically have six to twelve members that share a similar stressor or other similarity and receive expert information and training to learn to help one another to increase coping and adjustment (Gottlieb, 1998). Support groups are often times sought out when there is a deficiency in a persons natural support network (Helgeson & Gottlieb, 2000).

Of course traditional support groups and self-help groups are no longer the only place for someone seeking social support to turn to when their social network does not provide the support that is needed. We will now turn to an overview of the literature concerning online health-related support groups.

Online Social Support

With the widespread diffusion of the World Wide Web, many people have turned to online communities for support. In addition to the Internet serving as a widely accessible repository for cancer-related information, it has also become a veritable meeting ground for individuals with cancer to seek support from one another. Many research investigations in the last decade have documented the existence of online support communities for use for many different types of cancer including colorectal cancer (Klemm et al, 1998), breast cancer (Lieberman et al., 2003; Owen, Klapow, Roth, Nabell, & Tucker, 2004; Owen, Klapow, Roth, & Tucker, 2004; Till, 2003; Weinberg, Schmale, Uken, & Wessel, 1996; Winzlenberg et al., 2003), prostate cancer (Owen, Klapow, Roth, & Tucker, 2004), and leukemia (Ramos, Rai-Chaudhuri, & Neill, 2004).

Although not the first online support group, but perhaps the most well-studied, the Comprehensive Health Enhancement Support System (CHESS) designed by researchers at the University of Wisconsin – Madison, has come to be thought of as perhaps the quintessential example of successful online social support. CHESS is an online health-related support group focused on breast cancer and is one of the few online communities operated and maintained by a healthcare organization. CHESS was developed in 1987 by Dr. David Gustafson whose wife had been diagnosed with breast cancer. After the diagnosis, Dr. Gustafson and his wife were faced with numerous difficulties finding good informational and emotional support. Drawing on previous research on social support for patients and families experiencing serious illness, the aim of CHESS was to provide comprehensive support and information services to patients and their families. The overall goal for the researchers involved with CHESS was "to see individuals and family units cope more effectively with their crisis, suffer less, and feel like they'd made better decisions as a result of using CHESS" (CHESS, 2006).

CHESS offers a full range of condition-specific informational and social support services to patients and families in the comfort of their own home. Currently, CHESS has several different modules for different disease/conditions including breast cancer, HIV/AIDS, and stress management, among others.

There are a limited number of modules that CHESS offers for a limited number of conditions. For people who have a need to access CHESS, but do not have access to a computer, CHESS will loan a computer for up to one year. Because of the tightly controlled nature of CHESS, in order to gain access to the system, healthcare providers must purchase a license to the system (CHESS, 2006). Therefore, a limited number of people have access to CHESS when there is a very large potential market of people who are currently restricted from using the system.

Due to its strong affiliation with the University of Wisconsin – Madison, CHESS may be a breeding ground for online health community research, but it is not very prototypical of the majority of health-related online support groups. Numerous grants have been awarded to CHESS over the years and as such, they are able to offer services that most online support groups do not. In addition, the highly restricted nature of CHESS means that it is very heavily regulated. Because the service is administered through a health provider, access to the CHESS system is tightly controlled. Due to the fact that CHESS is so heavily regulated and purposefully administered, it does make a wonderful case study for the potential of online social support groups, but again, it is not very representative of the vast majority of online social support groups and the research conducted on the community is not very generalizable. The lack of generalizability for the research on CHESS ultimately requires more research to be conducted on more prototypical online communities.

Characteristics of Online Support Groups

Most online social support groups utilize mailing lists or listservs centered on particular health-related topics (White & Dorman, 2001). In comparison to their face-to-face counterparts, online health support communities are heavily utilized by sufferers of rare and debilitating conditions that may not be well understood in the medical community, may be difficult or impossible to cure, or have been commonly ignored by traditional healthcare such as chronic fatigue syndrome, multiple sclerosis, etc. (Davison, Pennebaker, & Dickerson, 2000). These online support communities can be used on their own or as a supplement to traditional face-to-face support groups for those patients who are in need of a greater amount of support (White & Dorman, 2001).

A study conducted by Cummings, Kiesler, & Sproull (2002) indicated that people with low levels of offline support (from family members and friends) are more likely than people who have high levels of offline support to participate and remain active in an online support community. In addition, those people with low levels of offline support particularly felt that they gained emotional and informational benefits from their participation in the online community. An investigation of online depression support groups has also found that users of online support groups tend to have less social support (Houston et al., 2002).

An investigation aimed at understanding SibKids, an online support group for children and adolescents who have a sibling with special needs, found that there were three types of support offered through the online community; emotional support, informational support, and social companionship (Tichon &

Yellowlees, 2003). These findings are similar to many other assessments of online support communities found in the online support community literature.

Reasons for Utilizing Online Health Support Communities

Regardless of disease or condition, health-related online support communities are used to find information, ask questions, share experiences, and seek/provide emotional support (Eysenbach et al., 2004; Lamberg, 2003; Ramos et al., 2004; White & Dorman, 2000). They allow community members to share their knowledge and experiences in order to add to collective group knowledge. Patients with diseases can offer to others valuable knowledge and insight regarding their condition (Lester, Prady, Finegan, & Hoch, 2004). It has been found that many users of online health communities report that the knowledge they gained through community involvement has helped them to make better decisions regarding treatment (Ramos et al., 2004). Winkelman and Choo (2003) argue that patients with chronic diseases can be quite knowledgeable about their condition and may be a great source of information for others. They further argue that for a whole host of reasons, healthcare organizations should embrace this and develop organizationally sponsored virtual communities for chronic patients. By relying on their knowledge and experience of a condition, along with the moderation of a healthcare professional, people suffering from chronic conditions can help to create more positive health outcomes for people in similar situations.

While the majority of online health communities are member created, in line with Winkelman and Choo's advice, we are currently seeing growth in the area of health provider sponsored communities. These communities are being created not only by health professionals, but by the pharmaceutical industry as a platform for advertising their own products, while providing useful services to the public. Healthcare providers have the potential to offer virtual community members a lot and should consider creating their own communities. Healthcare providers have the medical expertise needed to provide quality health information, they can expand their community range and reach by offering quick medical advice, and they can collect information gathered through data logs to track the technical capabilities of patients in order to provide better online services and product promotions (Butler, Friel, Lang, Park, & Santello, 2000).

Previous investigations have demonstrated that people are open to using the Internet for both health-related information and social support (Cudney & Weinert, 2000; Monnier, Laken, & Carter, 2002; Owen, Klapow, Roth, Nabell, & Tucker, 2004; Pierce et al., 2002). Due to the fact that the Internet offers confidentiality and ease of access (unlike talking with healthcare providers face-to-face), the Internet may also be an extremely attractive option for adolescents who are seeking potentially sensitive or embarrassing health-related information (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2004).

Utilization of online health support communities has also been shown to increase perceptions of the availability of social support (Barrera, Glasgow, McKay, Boles, & Feil, 2002). Although a limited number of investigations have tied online health support communities to health outcomes, there is some evidence that participation in these communities can lead to positive health outcomes (Lieberman et al., 2003). Through the use of computer-mediated communication, online social support groups have many advantages over their traditional face-to-face counterparts, though there are disadvantages as well.

Importance of Studying Online Social Support

Because online support groups are a relatively young phenomenon and because they may offer considerable advantages over traditional face-to-face support groups, it is important that we begin to study them from a social support perspective. By understanding their advantages and disadvantages, we may be better able to satisfy the needs of people seeking social support.

Advantages of Online Support

One of the most obvious advantages to the use of online support groups is the increased level of anonymity that the Internet affords (White & Dorman, 2001). In a traditional face-to-face setting, the chances of maintaining anonymity are quite small, but through computer-mediated conversation and the use of non-identifying pseudonyms, higher levels of anonymity can be maintained. Online support groups can also increase anonymity by reducing sociodemographic factors that would otherwise be obvious. These factors include race, gender, age, social status, etc. (Madara, 1997; O'Brien, 1999; Rheingold, 1993; White & Dorman, 2001). Because of this increased anonymity, people may be more willing to engage in online discourse regarding potentially embarrassing, sensitive, and/or taboo topics (Houston et al., 2002; Madara, 1997; Rhodes et al., 2003; Weinrich, 1997; White & Dorman, 2001).

Another great benefit of online support communities is the increased access provided by the medium. Through the use of asynchronous communication, these online health communities have the ability to transcend time and geographical constraints. They are available across the globe, all day, every day (Braithwaite, Waldron, & Finn, 1999; Houston et al., 2002; Lamberg, 2003; Madara, 1997; Ramos et al., 2004; White & Dorman, 2001). This has great implications for people who are homebound or possess other physical disabilities. In addition, the benefits to people in rural areas who may not have access to traditional support groups are great (Hill & Weinert, 2004; Madara, 1997). Lastly, the use of online support may be the only way for people with rare conditions to connect with other people who suffer from the same (Davison et al., 2000; White & Dorman, 2001).

Regarding cost, online support communities offer a low cost investment both in terms of time and monetary resources. Members of online support communities can contribute as much or as little time to participation as they wish. In terms of financial resources, most online communities are free and the only real barrier to access is the availability of a computer. While not every household has a computer, the number of people with access to the Internet is increasing. Current estimates state that 73% of adults and almost 90% of teenagers have access to the Internet (Madden, 2006).

Another great advantage to online support groups is that participation in online communities allows members to passively participate through lurking. Lurking occurs when a person reads messages within an online community, but does not post themselves. It has been suggested that the majority of members in online groups are lurkers and that despite the fact that they do not actively participate by posting, lurkers often feel a sense of community (Nonnecke & Preece, 2003). Speaking as a testament to the number of lurkers in online communities, an investigation by Perron (2002) indicated that many people who posted for the first time on a mental illness support community prefaced their contribution with the fact that they had been lurking for some time.

There are numerous reasons why people lurk. Among the top reasons for lurking include the individual belief that posting isn't necessary, needing to learn more about the community, the belief that individuals were helping the community by not posting, not being able to post due to software concerns, and/or poor fit between the individual and the community (Preece, Nonnecke, & Andrews, 2004). Although lurking can occur for many different reasons, it is important to note that people who lurk can still derive support without actually communicating with others within a community. Preece, Nonnecke, & Andrews (2004) discovered in an investigation on lurking that both lurkers and active participants primarily join online communities for the same reasons: to increase their understanding of a particular topic. In addition, within online health communities, it was found that both lurkers and active participants go to seek out social support.

Disadvantages of Online Support

Before a person can access an online support community, two requirements must be met; access to a computer and access to the Internet. Because there is a lack of universal access to the Internet, it is impossible for many people in this world to gain access to online communities (Braithwaite et al., 1999; Madara, 1997). While public access is becoming more and more available in the US, there still exists the possibility of a “digital divide” among the population (Madara, 1997).

In addition, in all computer-mediated settings, there exists a lack of contextual and social cues which may make communication more difficult. Not only can unintended meanings be interpreted through messages, but lack of context can often make communication impossible to understand. Because of this phenomenon, online community members are faced with the task of writing messages that are both clear and concrete (Perron, 2002).

Finally, a threat to online support communities is the great potential for researchers to exploit these communities through unethical research (Madara, 1997). Not only are researchers a potential threat, but so are advertisers, marketers, and other people who may visit a community for personal gain. When many community members make the decision to join an online community, there is little thought that they may potentially be the subjects of a research project. In fact, increasing evidence suggests that researchers that are lurking on online communities may be seen as intruders (Eysenbach & Till, 2001).

Summary

As more people utilize the Internet for communication and information related purposes, we will continue to see an increase in the number of people turning to online support groups. By researching online communities and understanding what they are used for, how they are utilized, and what the advantages and disadvantages are of social support in a computer-mediated environment, we may better understand the topic of social support in general. Due to the fact that messages in online communities are easily archived, studying social support on the Internet provides us with the ability to easily study social support in general. In addition, drawing comparisons between support interactions in electronic environments vs. real life environments will give us further understanding of how online and offline communities operate.

Because the field of social support, after all this time, still lacks a solid theoretical foundation, it is only reasonable that we continue to try to document the types of support interactions that are occurring both online and offline in a consistent manner. It is through continued research in both of these realms that we will be able to sort out what exactly social support is, how it is manifested in the real world, and how we can better assist people with real social support needs. Establishing a more comprehensive understanding of social support, both online and offline, has enormous implications for all aspects of how we aid people with support needs. By having a more complete view of social support, we will be able to design, structure, and implement support services more efficiently and effectively both in the online and offline worlds.

This investigation sought to investigate online support communities for cancers with varying five-year relative survival rates. In addition to understanding who is utilizing these communities in terms of gender and community member role, this study also sought to understand the different types of social support interactions that are occurring within these online spaces. This study utilized Optimal Matching Theory as a theoretical framework for understanding the different types of social support that occur within eight cancer-related online support groups. Optimal Matching Theory is an appropriate theoretical framework for this study due to the fact that it is not context dependent and can help us to understand the types of social support interactions that are occurring in an online environment. In addition, by utilizing Optimal Matching Theory as a theoretical framework, predictions related to different social support type frequencies within each community could be made, serving to guide us in this investigation, as well as testing the theory in this electronic context. Finally, Optimal Matching Theory is a useful theoretical framework for helping to understand participation in online support communities because it gives us insight into why some members of a community persist over very long periods of time, whereas some members only visit once or twice. For those members who participate in an online support community over time, it is reasonable to assume that they do so because their support needs are being met. This suggests that members who continue to participate in an online community have found successful support matches. For those members who only visit a community once or twice, it is also reasonable to assume that they do so because their needs are not being met and a successful support match has not been made.

This investigation of social support interactions within online health-related communities differs from many other social support investigations in that social support interactions are of primary interest, not specific measures of social support as identified through the use of questionnaires or inventories. While this is not a novel approach to studying social support, it is a far less utilized strategy.

Compared to the number of investigations of social support that exist in the literature, the approach of describing and analyzing social support interactions has been utilized in a relatively few number of studies focused on online health-related support communities.

Although previous studies have utilized a similar research design to the one in this investigation, these previous studies had several weaknesses that this investigation attempts to overcome. First of all, prior studies lacked generalizability as they were either case studies or investigations that included a very small number of communities, making cross community comparisons either impossible or difficult (Blank & Adams-Blodnieks, 2007; Dunham et al., 1998; Klemm et al., 1998; Lasker, Sogolow, & Sharim, 2005; Mendelson, 2003; Owen, Klapow, Roth, & Tucker, 2004; Perron, 2002; Tichon & Shapiro, 2003; Weinberg et al., 1996; White & Dorman, 2000). To overcome this shortcoming in previous literature, this investigation compared eight online support communities in an effort to establish the beginnings of generalizability of this line of research.

Second, the methodologies of previous content analysis studies were often compromised as no measures of inter-coder reliability were reported (Blank & Adams-Blodnieks, 2007; Klemm et al., 1998; Mendelson, 2000; White & Dorman, 2000;). This investigation attempted to overcome this failing in previous literature by establishing sound methodological practices through the use of multiple coders and the establishment of an acceptable level of intercoder reliability.

Another shortcoming of previous research has been the use of very small sample periods, making generalizability difficult. Similar investigations have analyzed data from nine days (Klemm et al., 1998), two months (Klemm & Wheeler, 2005; Lasker et al., 2005; Owen, Klapow, Roth, & Tucker, 2004), or even three months (Mendelson, 2003; Pierce et al., 2002; Tichon & Shapiro, 2003). This investigation included one randomly selected week from each month over a one year time period in an effort to expand the sample size and cover a wider period of time. Finally, this study moves beyond similar research by trying to understand how the role of a community member impacts social support provision within online support communities.

Research Questions and Hypotheses

In order to better understand the ways in which social support is provided in online support communities, as well as test Optimal Matching Theory, a series of three research questions and three hypotheses were developed to guide this investigation. These research questions and hypotheses specifically address how different factors influence social support provisions within online support communities, as well as whether or not controllability has the influence on support provisions that OMT indicates.

- RQ1: What is the effect of community member role on online cancer support communities?
    a. Who are the users of online cancer support communities (patient, family member, medical professional, cancer survivor, etc.)?

    b. What types of social support do community members with different roles provide and how frequently is each type provided?

- RQ2: What is the effect of five-year relative cancer survival rate on online cancer support communities?
    a. Does the survival rate of a specific cancer impact online community membership composition (both in terms of gender and community member role)?
    b. How does cancer survival rate impact the types and amounts of emotional and informational support within communities?

- RQ3: Are there specific characteristics of communities that impact social support provision in online cancer support communities?
    a. Does the community host (cancer-specific vs. general use) impact the types and frequency of social support provisions or the membership of online cancer communities (both in terms of community member role and gender)?
    b. Does the private or public nature of a community impact the types and frequency of social support provisions or the membership of online cancer communities (both in terms of community member role and gender)?
    c. Does the volume of posts within a community impact the types and frequency of social support provisions or the membership of online

cancer communities (both in terms of community member role and gender)?

d. Does the size of a community impact the types and frequency of social support provisions or the membership of online cancer communities (both in terms of community member role and gender)?

To further guide this investigation, three hypotheses were created. Based on the research previously discussed regarding gender and social support, specifically research that indicates that women tend to provide social support more frequently than men (Belle, 1982; Fischer, 1982; Griffith, 1985; Kendler et al., 2005; Kessler et al., 1985; Trobst et al., 1994), are more likely to join support groups (Krizek et al., 1999), that current members of support groups are more likely to be female (Grande et al., 2006; Moos et al., 2006), and that women are more likely than men to provide emotional support and men are more likely than women to provide informational support (Klemm et al., 1999; Rosenthal et al., 1986; Seale et al., 2006; Sullivan, 2003), it was hypothesized that: These expectations were based on previous research indicating that.

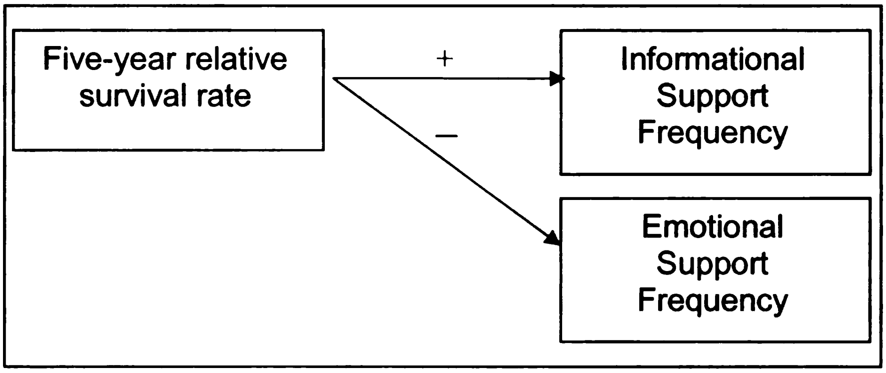
- *H1a: There will be a larger proportion of women in the online support communities than men.*
- *H1b: Women will post more messages than men.*
- *H1c: Women will provide a greater proportion of emotional support than men.*

- *H1d: Men will provide a greater proportion of informational support than women.*

Based on Optimal Matching Theory, as controllability was considered to be the most important factor in influencing social support types, hypotheses two and three were created utilizing five-year relative survival rate as a proxy for controllability. Figure 1 provides a graphical depiction of these two hypotheses.

- *H2: There will be a greater proportion of emotional support provision in communities for cancers with low five-year relative survival rates as opposed to communities for cancers with high five-year relative survival rates.*
- *H3: There will be a greater proportion of informational support provision in communities for cancers with high five-year relative survival rates as opposed to communities for cancers with low five-year relative survival rates.*

Figure 1: Graphical Representation of Hypotheses Two and Three



Chapter 3: Methodology

In order to address the research questions and hypotheses set forth in the preceding chapter, a quantitative content analysis was conducted on 3,717 message postings located in eight different health-related online support communities focused on four different types of cancer. As defined by Riffe, Lacy, & Fico (2005, pg. 25) "quantitative content analysis is the systematic and replicable examination of symbols of communication, which have been assigned numeric values according to valid measurement roles and the analysis of relationships involving those values using statistical methods, to describe the communication, draw inferences about its meaning, or infer from the communication to its context, both of production and consumption." Because research questions concerned determinations regarding the content of posts made within online support communities, content analysis was deemed the appropriate method to investigate these particular questions. It should be noted that the methods used in this investigation were approved by the Michigan State University institutional review board.

Sample

When determining community hosts for this investigation, two contrasting websites hosting online cancer support communities were chosen; Yahoo! and ACOR (Association of Cancer Online Resources). Of the eight communities located in this sample, four were hosted by Yahoo!Groups and four were hosted by the ACOR. Yahoo!, one of the most recognizable names in the online realm, "is a leading global Internet communications, commerce and media company that offers a comprehensive branded network of services to more than 345 million individuals each month worldwide" (Yahoo, 2005).Yahoo! is known for being one of the world's most prominent search engines and Internet portals. In addition to the many information services offered within the Yahoo! portal, as of February, 2007, over 37,000 electronic support groups, over 10,000 electronic fitness and nutrition groups, and over 2,500 electronic drug and medication groups had been listed by Yahoo!Groups under the "health and wellness" category. Yahoo!Groups was selected for inclusion in this study because Yahoo! is a popular information portal familiar to many Internet users. Due to the fact that they do not dedicate their services to any particular topic, Yahoo! is a destination for a very diverse audience and users do not necessarily visit Yahoo! strictly for cancer-related information.

Regarding ACOR, founded in 1996, it has become one of the largest and most well known websites for online support communities focused on cancer, as well as other cancer-related information, available on the Internet. With approximately 200 public and private listservs devoted to different types of cancer and cancer-related issues, an average of 200,000 email messages are sent through ACOR listservs per day (L-Soft, 2005). As such, ACOR has grown to be an incredibly valuable asset in the online social support community. ACOR was selected for inclusion in this study because the ACOR website is devoted strictly to cancer-related information, resources, and support. Users of ACOR utilize the site primarily for these purposes. As ACOR requires users to register for the various communities before being able to access the community archives, permission to utilize the archives for this investigation was obtained by Gilles Frydman, the founder of ACOR.

The eight different communities included in this investigation were focused on four different types of cancer with two communities for each cancer type. For each cancer type, one community was hosted by ACOR and the other by Yahoo!Groups. Cancer types were further divided into high and low five-year relative survival rate conditions. To truly make the distinction between high and low five-year relative survival rates, cancer types were chosen according to cancers with the highest and lowest five-year relative survival rates as reported by the American Cancer Society. The low five-year relative survival rate condition included cancers with a less than 20% five-year relative survival rate, while the high five-year relative survival rate condition included cancers with a more than 80% five-year relative survival rate. The high five-year relative survival rate condition included communities focused on melanoma and thyroid cancer, two types of cancer that have very high five-year relative survival rates (91.5% and 96.7% respectively across all stages) (American Cancer Society, 2007). The low five-year relative survival rate condition included communities devoted to pancreatic and lung cancer, two cancers with very low five-year relative survival rates (5.0% and 15.0% respectively across all stages) (American Cancer Society, 2007).

This investigation utilized a stratified sample of twelve weeks of posts from each of the eight online support communities. In order to control for seasonality, one week (considered to be a seven day period starting on Sunday) was randomly selected from each month between July 2005 and July 2006. Weeks that were partially included in two different months were considered to fall in the month in which the initial Sunday occurred. It is important to control for seasonality as particular times of the year (particularly around holidays), may not necessarily be representative of the types of interactions that occur throughout the year.

Once the weeks were identified, all eight communities were evaluated according to the same randomly selected time periods. In the event that it wasn't possible to stratify the sample due to small sample size, a census of message postings from the corresponding one year time period was used. The final sample included 3,717 posts across all eight communities. For a complete listing of the number of postings located in each community, please refer to Table 1. The content analyzed in this study consisted of individually posted messages located in the eight different online communities and the unit of analysis was the individual messages. All archived messages from our sampling period were included in this investigation.

Data Collection

In order to content analyze the postings in this study, a coding protocol based on the independent and dependent variables under investigation was developed (Appendix B). This coding protocol clearly defined each variable, as well as the coding procedures.

Independent Variables

For the purposes of this study, seven distinct independent variables were identified: gender, community member role, five-year relative survival rate, community host, community openness, community post volume, and community size. The first independent variable, community member gender, was coded as a nominal level variable based on sex; male and female. In instances where gender could not be identified, community members were coded as having an unidentified gender. The gender of community members was identified using contextual clues located within postings.

The second independent variable under investigation in this study was community member role. Roles were coded as a nominal level variable and community members were categorized as patient (person suffering from disease), spouse/partner, child of patient, parent of patient, other family member of patient, medical professional, volunteer/activist, friends, other, or unclassified. Community member roles were identified using contextual clues located within postings. Because there were so few community members who were considered to be medical professionals, volunteer/activists, or friends of patients, these categories were collapsed into the "other" category.

Our third independent variable, five-year relative survival rate, was determined according to the statistics published yearly by the American Cancer Society. For our purposes, five-year relative survival rate was coded with values of low and high. The high five-year relative survival rate cancer communities of interest in this investigation were focused on melanoma (91.5% five-year relative survival rate across all stages) and thyroid cancer (96.7% five-year relative survival rate across all stages), and the low five-year relative survival rate cancer communities of interest are focused on pancreatic cancer (5.0% five-year relative survival rate across all stages) and lung cancer (15.0% five-year relative survival rate across all stages) (American Cancer Society, 2007). Because this variable was determined prior to the start of this study, coders did not need to make a determination regarding high vs. low five-year relative survival rates.

The fourth independent variable, community host type, was coded as a nominal level variable with two values; general purpose and cancer-specific. As Yahoo! is a general purpose portal and has hundreds of thousands of online communities spanning a wide variety of topics, all posts located in a Yahoo!Groups community were coded as being hosted by a general purpose host. Due to the fact that ACOR was developed as a cancer-specific domain and all communities located within the site are cancer-specific, all posts located in an ACOR community were coded as being hosted by a cancer-specific host. Because this variable was determined prior to the start of this study, coders did not need to make a determination regarding community host type.

Openness, the fifth independent variable in this investigation, describing whether or not a community was public (meaning anyone had access to the archives) or private (meaning Internet users have to register with the community before gaining access to the archives) was coded as a nominal level variable. Because this variable was determined prior to the start of the study, coders did not need to make a determination regarding whether a community was considered to be public or private.

The sixth independent variable in this investigation, community size, was based on the number of registered members that participated during the sample period. Community size was coded on a nominal level after the coding of the sample was finished. Those communities that had a large community size had more than 100 active participants during the sample period, while those communities that had a small community size had less than 65 active participants during the sample period.

Finally, community post volume served as the seventh independent variable in this investigation. Community post volume described the number of posted messages during the sample period and was coded on a nominal level. Communities were either coded as having a low post volume or a high post volume. Those communities that had a low post volume had less than 300 postings included in the sample, while the communities that had a high post volume had more than 500 postings included in the sample. Because this variable was determined prior to the start of the study, coders did not need to make a determination regarding whether a community was considered have a high or low post volume.

Dependent Variable

In regards to our dependent variable, social support provisions, it is widely accepted that there are three primary types of support that one can give/receive including emotional, informational, and instrumental (direct assistance) support.

For the purposes of this investigation, support provision type was coded on a nominal level according to the presence or absence of each type of support provision and the different support subtypes. The different subtypes of informational and emotional support were determined through thematic content analysis. Each of the social support subtypes fit into the larger Optimal Matching Theory as either being action-facilitation (known from here on as informational support) or nurturant (known from here on as emotional support). It should be noted that the emotional support subtypes developed through thematic content analysis were guided by previous work by Klemm, Reppert, and Visich (1998) and White & Dorman (2000). For a complete listing of the different subtypes of emotional and informational support and their operationalizations, please see Appendix B.

Regarding the notion of instrumental or tangible aid support, because of the limits placed on human interaction within an electronic environment, the only way to provide a person with instrumental support is to provide information. Therefore, instrumental support in its purest form is not possible in an electronic environment. To account for this, coders were trained to identify interactions where instances of instrumental support were discussed between two community members.

Reliability

Because this investigation utilized a content analysis methodology, the establishment of intercoder reliability was essential. Intercoder reliability refers to "the extent to which independent coders evaluate a characteristic of a message or artifact and reach the same conclusion" (Lombard, Snyder-Duch, & Bracken, 2002, p. 589). In order to establish intercoder reliability, two investigators were trained on the coding protocol. After extensive training and practice, each coder independently analyzed a subsample consisting of 186 messages (5% of the total sample). Previous work has indicated that 5% of the total sample is a suitable sample size for establishing intercoder reliability (Kaid & Wadsworth, 1989). The messages included in this subsample were randomly selected using a random number generator. To be sure that an appropriate level of intercoder reliability had been achieved, it was predetermined that all variables needed to receive a Cohen's Kappa agreement of at least .85 or higher in order for coding to commence. Cohen's Kappa is a conservative statistical index that accounts for chance agreement between two coders (Lombard, Snyder-Duch, & Bracken, 2002). The .85 level was deemed to be acceptable because not only is Cohen's Kappa a conservative statistic, but a recent review of "rules of thumb" for deciding appropriate levels of reliability determined that coefficients of ".90 or greater would be acceptable to all, .80 or greater would be acceptable in most situations, and below that, there exists great disagreement" (Neuendorf, 2002). In addition, it has been suggested that most research reports reliability that is .80 or higher (Riffe et al., 2005).

Data Analyses

Once the data had been collected, descriptive statistics were employed to describe the frequencies of different types of social support activity according to community member gender, role, five-year relative survival rate, community host, community openness, community post volume, and community size. Chi-square analyses were used to make comparisons within and between independent variables in regards to social support type frequencies. Although social support subtypes were reported, in an effort to make the data more meaningful, social support subtypes were collapsed into the overarching categories of emotional and informational support for data analysis purposes.

Now that the methodology of this study has been presented, in chapter four, the results of this investigation are presented. To help structure the presentation, results are presented according to the research question in which they are related.

Chapter 4: Results

The primary objective of this investigation was to investigate online support communities for cancers with varying five-year relative survival rates. In addition to understanding who is utilizing these communities in terms of gender and community member role, this study also sought to understand the different types of social support provisions that are occurring within these online spaces. The purpose of this chapter is to present the findings of this investigation. First, an overall description of the posting activity within the communities is presented followed by the primary results as structured by research questions and hypotheses. A discussion of the results presented here will be presented in chapter five.

Posting Activity

In total, there were 3,717 posts included in the sample period, written by 587 unique community members. Posting activity of community members varied greatly among the 587 unique community members that posted during the sample period. Number of posts by unique posters ranged from 1 to 245 posts (M=6.3 posts per member, Median = 2.0 posts per member, SD = 14.52). For the complete breakdown of number of posts and unique posters per community, see Table 1.

Overall, 2,255 messages (60%) in the total sample contained at least one instance of social support provision. The remaining 40% of messages contained instances of emotional and/or informational support seeking, messages that were related to cancer, but did not contain social support, or off topic posts not related to cancer. Of those messages that contained social support provisions, the number of social support subtype themes ranged from one to six different themes per message (M=1.5, SD=.85). Data analysis revealed significant differences in the number of messages providing social support across the eight communities, χ^2 (7, n = 3,717) = 66.41, p<.05, and a one way analysis of variance revealed that there were significant differences in the average number of themes for messages that included social support across the eight communities, F(7, 2,247) = 7.46, p <.05. This means that communities differed in the number of posts containing social support provisions, as well as the average number of support themes within messages.

At least one type of social support provision occurred in approximately half or more of the postings within each community. The ACOR melanoma community (high five-year survival rate condition) had the lowest percentage of messages containing at least one social support provision (49%) and the Yahoo!Groups pancreatic cancer community (low five-year survival rate condition) had the highest percentage (72%). Table 1 shows a complete breakdown of the percentage of messages within each community that contained at least one instance of social support provision.

Table 1: Community Descriptors

	Total Number of Posts (n=3,717)	Total Number of Unique Posters (n=587)	% of Posts Containing Social Support Provisions	Average Number of Social Support Provision Themes per Message per Community
Yahoo: Melanoma	122	45	62%	1.53
Yahoo: Thyroid Cancer	944	53	51%	1.45
Yahoo: Pancreatic Cancer	272	48	72%	1.79
Yahoo: Lung Cancer	894	135	65%	1.56
ACOR: Melanoma	81	27	49%	1.58
ACOR: Thyroid Cancer	286	64	60%	1.33
ACOR: Pancreatic Cancer	523	101	61%	1.64
ACOR: Lung Cancer	595	114	65%	1.25

Regarding social support provision type, 1,311 messages (58%) included only instances of emotional support provision, 687 messages (30%) contained only instances of informational support provision, and 257 messages (11%) contained instances of both emotional and informational support provision. Table 2 provides a complete breakdown of the type of support included in messages containing social support within each community.

Table 2: Frequency of Social Support Type by Community

	Type of Social Support Provision Present							
	Yahoo: Melanoma (n=76)	Yahoo: Thyroid Cancer (n=484)	Yahoo: Pancreatic Cancer (n=196)	Yahoo: Lung Cancer (n=584)	ACOR: Melanoma (n=40)	ACOR: Thyroid Cancer (n=172)	ACOR: Pancreatic Cancer (n=318)	ACOR: Lung Cancer (n=385)
Informational Support Only	33%	12%	47%	17%	30%	55%	32%	52%
Emotional Support Only	50%	80%	41%	73%	45%	33%	50%	39%
Both Informational and Emotional Support	17%	8%	12%	10%	25%	12%	19%	9%
Total	100%	100%	100%	100%	100%	100%	101%*	100%

* Does not add up to 100% due to rounding error.

As for the subtypes of support that were provided during the sample period, Tables 3 and 4 provide a complete listing of the emotional and informational support subtypes and their frequencies in each community. Data indicate that in all eight communities, *encouragement* was the most frequently represented emotional support subtype while *welcoming* and *offers for contact* were the least frequently represented. Regarding informational support, consistently across all eight communities, *mediated information* and *medical information* were the most frequently represented informational support subtypes while *live assistance information* was consistently the least frequently represented.

Table 3: Emotional Support Types and their Frequency by Community

	Emotional Support Subtypes							
	Yahoo: Melanoma (n=66)	Yahoo: Thyroid Cancer (n=583)	Yahoo: Pancreatic Cancer (n=210)	Yahoo: Lung Cancer (n=738)	ACOR: Melanoma (n=34)	ACOR: Thyroid Cancer (n=87)	ACOR: Pancreatic Cancer (n=314)	ACOR: Lung Cancer (n=242)
Prayer/Spiritual	17%	10%	25%	20%	9%	5%	17%	8%
Understanding	9%	19%	20%	14%	15%	15%	11%	11%
Sympathy		6%	16%	13%	3%	1%	14%	15%
Welcoming	2%	3%	1%	3%			1%	4%
Encouragement	64%	61%	35%	47%	71%	77%	51%	59%
Offers for Contact	9%	1%	3%	3%	3%	2%	7%	2%
Total	101%*	100%	100%	100%	101%*	100%	101%*	99%*

* Does not add up to 100% due to rounding error.

Table 4: Informational Support Types and their Frequency by Community

	Informational Support Subtypes							
	Yahoo: Melanoma (n=50)	Yahoo: Thyroid Cancer (n=118)	Yahoo: Pancreatic Cancer (n=140)	Yahoo: Lung Cancer (n=183)	ACOR: Melanoma (n=29)	ACOR: Thyroid Cancer (n=141)	ACOR: Pancreatic Cancer (n=208)	ACOR: Lung Cancer (n=290)
Mediated	40%	24%	54%	25%	21%	38%	29%	45%
Live Assistance	8%	7%	1%	5%		6%	17%	8%
Disease/Symptom	12%	16%	14%	9%	31%	18%	6%	8%
Medical Information	22%	42%	23%	44%	31%	28%	28%	26%
General Information	18%	12%	8%	17%	17%	10%	20%	14%
Total	100%	101%*	100%	100%	100%	100%	100%	101%

* Does not add up to 100% due to rounding error.

RQ1: Community Member Role

The first research question concerned the effect of community member role on online cancer support communities. Results indicate that the largest group of posters during the sample period was patients (34%). In addition, there were also large numbers of individuals who were classified as a spouse/partner (18%) or child of a patient (18%). Overall, 17% of unique posters were unclassifiable and the remaining community members were either parents of patients (2%), other family members of patients (8%) or were classified as "other' (4%). A significant relationship between community member role and community participation was found, $\chi^2(42, n = 587) = 181.27$, $p<.05$, meaning that the demographic composite of community members in terms of role varied by community. This finding should be taken with a grain of salt as more than 10% of the cells within this table had fewer than five cases. Table 5 provides a complete breakdown of the role of unique posters for each community.

Table 5: Frequency of Community Member Roles across Communities[+]

	Community Member Role						
	Unclassified (n=98)	Patient (n=202)	Spouse/Partner (n=103)	Child of Patient (n=104)	Parent of Patient (n=14)	Other Family Member of Patient (n=45)	Other (n=21)
Yahoo: Melanoma	13%	9%	6%	3%	14%	4%	5%
Yahoo: Thyroid Cancer	3%	21%	2%		29%		5%
Yahoo: Pancreatic Cancer	10%	2%	9%	15%		16%	14%
Yahoo: Lung Cancer	26%	14%	25%	35%	7%	31%	19%
ACOR: Melanoma	6%	4%	5%	2%	14%	7%	10%
ACOR: Thyroid Cancer	13%	20%	2%	1%	7%	4%	19%
ACOR: Pancreatic Cancer	8%	11%	26%	26%	21%	20%	24%
ACOR: Lung Cancer	20%	19%	25%	18%	7%	18%	5%
Total	99%*	100%	100%	100%	99%*	100%	101%*

* Does not add up to 100% due to rounding error.

[+] More than 10% of cells in this table have fewer than five cases per cell.

$\chi^2(42, n = 587) = 181.272, p<.05$.

In addition to making up the majority of unique posters, patients also posted the majority of the posts containing social support provisions during the sample period. Of the 2,255 messages containing social support, 1,067 messages (47%) were posted by patients, 409 messages (18%) were posted by spouse/partners, 266 messages (12%) were posted by children of patients, 271 messages (12%) were posted by other family member of patients, 27 messages (1%) were posted by parents of patients, 66 messages (3%) were posted by individuals classified as “other”, and 149 of messages (7%) were posted by community members whose role was unclassifiable. The relationship between community member role and the posting of messages with social support provision was found to be significant $\chi^2(42, n = 2{,}255) = 1{,}255.11, p<.05$, meaning that the frequency of posting messages with social support provisions by different groups of community member roles varied by community. Please see Tables 5 and 6.

Table 6: Frequency of Social Support by Role across Communities

	Community Member Role						
	Unclassified (n=149)	Patient (n=1067)	Spouse/Partner (n=409)	Child of Patient (n=266)	Parent of Patient (n=27)	Other Family Member of Patient (n=271)	Other (n=66)
Yahoo: Melanoma	8%	5%	1%	2%	7%	.4%	3%
Yahoo: Thyroid Cancer	1%	43%	3%		59%		
Yahoo: Pancreatic Cancer	5%	.3%	11%	12%		32%	32%
Yahoo: Lung Cancer	38%	16%	40%	46%		24%	11%
ACOR: Melanoma	3%	2%	2%	1%	15%	1%	2%
ACOR: Thyroid Cancer	15%	11%	1%		7%	2%	33%
ACOR: Pancreatic Cancer	2%	8%	26%	26%	11%	16%	17%
ACOR: Lung Cancer	28%	16%	16%	13%		25%	3%
Total	100%	101%*	100%	100%	99%*	100%	101%*

* Does not add up to 100% due to rounding error.
χ^2(42, n = 2,255) = 1,255.11, p<.05.

Regarding social support provision, data indicate that patients, spouse/partners, children of patients, and parents of patients provided a greater percentage of purely emotional support than purely informational support or informational and emotional support combined. Not including those classified as "other", family members of patients who were not spouse/partners, parents, or children provided the greatest percentage of purely informational support (55%) and the lowest percentage of purely emotional support (34%), while children of patients provided the largest percentage of purely emotional support (72%) and parents of patients provided the smallest percentage of purely informational support (11%) across all communities. Data indicate that community member role was significantly related to social support provision type, $\chi^2(12, n = 2,255) = 233.32, p<.05$. This indicates that the different types of social support provision varied by community member role. Please see Table 7 for a complete for a complete breakdown of social support provisions by role.

Table 7: Frequency of Social Support Type by Community Member Role

	Community Member Role						
	Unclassified (n=149)	Patient (n=1067)	Spouse/Partner (n=409)	Child of Patient (n=266)	Parent of Patient (n=27)	Other Family Member of Patient (n=271)	Other (n=66)
Informational Support Only	46%	23%	28%	19%	11%	55%	80%
Emotional Support Only	46%	65%	57%	72%	70%	34%	15%
Both Informational and Emotional Support	8%	11%	15%	9%	19%	11%	5%
Total	100%	99%*	100%	100%	100%	100%	100%

* Does not add up to 100% due to rounding error.
$\chi^2(12, n = 2,255) = 233.32, p<.05$.

RQ2: Five-Year Relative Survival Rate

The second research question addressed the effect of five-year relative survival rate on online cancer support communities. In terms of gender and participation in high and low survival rate communities, results indicate that these variables were not significantly related, $\chi^2(2, n = 587) = .07, p>.05$, meaning that men and women were just as likely to belong to high survival rate communities as they were to low survival rate communities. Table 8 provides a complete breakdown of unique community member gender and participation in high and low five-year relative survival rate communities.

Table 8: Frequency of Gender Participation by Cancer Survival Rate

	Five-Year Relative Survival Rate	
	Low (n=398)	High (n=189)
Male	20%	19%
Female	66%	66%
Unclassified	14%	15%
Total	100%	100%

χ^2 (2, n = 587) = .07, p>.05.

Despite the fact that gender and participation in communities for varying survival rate cancers was not found to be significantly related, data analysis indicated that there was a significant relationship between gender and social support provision according to survival rate, χ^2 (2, n = 2,255) = 47.19, p<.05. While women posted a larger proportion of messages containing social support provision than men regardless of survival rate, males posted a larger proportion of messages with social support provisions in the high survival rate condition (29%) than they did in the low survival rate condition (16%), whereas women posted a larger proportion of messages with social support provisions in the low survival rate condition (77%) than they did in the high survival rate condition (67%). Table 9 provides a complete breakdown of gendered postings that included social support provisions by survival rate.

Table 9: Frequency of Gendered Social Support by Cancer Survival Rate

	Survival Rate	
	Low (n=1,483)	High (n=772)
Male	16%	29%
Female	77%	67%
Unclassified	7%	5%
Total	100%	101%

* Does not add up to 100% due to rounding error.
χ^2(2, n = 2,255) = 47.19, p<.05.

Regarding community member role and participation in high vs. low survival rate communities, results indicate that patients made up the largest proportion of community members in low survival rate communities (58%). In the high survival rate condition, patients (23%), spouses/partners (22%) and children of patients (25%) made up almost equal proportions. The relationship between community member role and participation in high vs. low survival rate communities was found to be significant, χ^2(6, n = 587) = 104.97, p<.05, indicating that the demographic composite of community members in terms of role varied by the survival rate of the community. Furthermore, not only was there a significant relationship between community member role and membership in high and low survival rate communities, but there was also a significant relationship between community member role and contributions of messages that contain social support provisions within high and low survival rate communities, χ^2(6, n = 2,255) = 349.48, p<.05, meaning that the frequency in which different community member role groups posted messages with social support varied by the survival rate of the community. Patients by far contributed the largest proportion of messages that contain social support provisions to the high survival rate condition (82%), while patients and spouse/partners contributed the largest proportions of postings to the low survival rate condition (29% and 26% respectively). Please see Tables 10 and 11 for a complete breakdown of community member roles and their participation and frequency of posting messages with social support in high and low survival rate communities.

Table 10: Frequency of Role Participation by Cancer Survival Rate

	Five-year Relative Survival Rate	
	Low (n=398)	High (n=189)
Unclassified	19%	16%
Patient	58%	23%
Spouse/Partner	8%	22%
Child of Patient	3%	25%
Parent of Patient	5%	1%
Other Family Member of Patient	4%	10%
Other	4%	3%
Total	101%*	100%

* Does not add up to 100% due to rounding error.
$\chi^2(6, n = 587) = 104.97, p<.05$.

Table 11: Frequency of Social Support by Role by Cancer Survival Rate

	Five-year Relative Survival Rate	
	Low (n=1,483)	High (n=772)
Unclassified	7%	5%
Patient	29%	82%
Spouse/Partner	26%	4%
Child of Patient	17%	1%
Parent of Patient	.2%	3%
Other Family Member of Patient	18%	1%
Other	3%	3%
Total	100%	99%*

* Does not add up to 100% due to rounding error.
$\chi^2(6, n = 2{,}255) = 707.79, p<.05$.

RQ3: Additional Community Characteristics

The final research question concerned whether or not there were additional community characteristics that impact online cancer support communities. To determine whether or not there were features of communities that were significantly related to social support provision and the demographic makeup of the communities in terms of gender or community member role, four features were identified and analyzed. These features included the community host, openness of the community (whether it is public or private), volume of postings within the community, and the size of the community in terms of the number of registered community members. Each of these four variables are now discussed.

Host

The relationship between gender and participation in communities with different hosts was found to be significant, χ^2 (2, n = 587) = 16.34, $p<.05$, as was the relationship between gender and frequency of posting messages with social support in communities with different hosts, χ^2 (2, n = 2,255) = 8.04, $p<.05$. This means that the gender breakdown of community members varied by community host, as did the frequency with which differently gendered community members posted messages with social support messages. Please see Tables 12 and 13.

Table 12: Frequency of Gender Participation by Community Host

	Community Host	
	Yahoo! (n=281)	ACOR (n=306)
Male	17%	22%
Female	63%	69%
Unclassified	20%	9%
Total	100%	100%

χ^2 (2, n = 587) = 16.34, p<.05.

Table 13: Frequency of Gendered Social Support by Community Host

	Community Host	
	Yahoo! (n=1340)	ACOR (n=915)
Male	19%	23%
Female	74%	73%
Unclassified	7%	5%
Total	100%	101%*

* Does not add up to 100% due to rounding error.
χ^2 (2, n = 2,255) = 8.04, p<.05.

Regarding community member role and participation in communities with different hosts, no significant relationship was found, χ^2 (6, n = 587) = 3.98, p>.05, indicating that community members with different roles were no more likely to belong to Yahoo! than they were to ACOR. Despite this fact, a significant relationship was found between community member role and frequency of posting messages with social support provisions in communities with different hosts, χ^2 (6, n = 2,255) = 21.69, p<.05, meaning that the frequency that different community member role groups posted messages with social support varied by community host. Please see Tables 14 and 15.

Table 14: Frequency of Role Participation by Community Host

	Community Host	
	Yahoo! (n=281)	ACOR (n=306)
Unclassified	18%	15%
Patient	33%	36%
Spouse/Partner	15%	20%
Child of Patient	20%	16%
Parent of Patient	3%	2%
Other Family Member of Patient	8%	7%
Other	3%	4%
Total	100%	100%

χ^2 (6, n = 587) = 3.98, p>.05.

Table 15: Frequency of Social Support by Role by Community Host

	Community Host	
	Yahoo! (n=1340)	ACOR (n=915)
Unclassified	6%	8%
Patient	51%	43%
Spouse/Partner	17%	20%
Child of Patient	12%	12%
Parent of Patient	1%	1%
Other Family Member of Patient	11%	13%
Other	2%	4%
Total	100%	101%*

* Does not add up to 100% due to rounding error.
χ^2 (6, n = 2,255) = 21.69, p<.05.

Finally, results indicate that a greater proportion of messages containing only emotional support were posted in Yahoo!, while a greater proportion of messages containing only informational support were posted in ACOR. The relationship between community host and the frequency of postings with strictly emotional support provision, strictly informational support provision, and postings with both types of support provision was found to be significant, χ^2 (2, n = 2,255)

= 178.25, $p<.05$, meaning that the types of social support messages in online cancer communities varied by community host. Please see Table 16.

Table 16: Frequency of Social Support Type by Community Host

	Community Host	
	Yahoo! (n=1,340)	ACOR (n=915)
Informational Support Only	21%	45%
Emotional Support Only	69%	42%
Both Informational and Emotional Support	10%	13%
Total	100%	100%

χ^2 (2, n = 2,255) = 178.25, $p<.05$.

Openness

Data analysis indicated that although males made up an equal proportion of community members in public and private communities, a larger proportion of females belonged to private communities. The relationship between gender and participation in communities that were public vs. private was found to be significant, χ^2 (2, n = 587) = 17.46, $p<.05$, meaning that the participation of males and females in online support communities for cancer varied by whether or not the community was public or private. Results also indicate that females posted a greater proportion of messages with support provisions in private communities (76%) than they did in public communities (53%), while males posted a greater proportion of messages with support provisions in public communities (31%) than they did in private communities (19%). The relationship between gender and the posting of messages containing instances of social support provision in public or private communities was also found to be significant, χ^2 (2, n = 2,255) = 83.18, p<.05. Please see Tables 17 and 18.

Table 17: Frequency of Gender Participation by Community Openness

	Openness	
	Public (n=93)	Private (n=494)
Male	19%	19%
Female	53%	69%
Unclassified	28%	12%
Total	100%	100%

χ^2 (2, n = 587) = 17.46, p<.05.

Table 18: Frequency of Gendered Social Support by Community Openness

	Openness	
	Public (n=272)	Private (n=1983)
Male	31%	19%
Female	53%	76%
Unclassified	16%	5%
Total	100%	100%

χ^2 (2, n = 2,255) = 83.18, p<.05.

Regarding community member role and participation in communities that were public vs. private, no significant relationship was found, χ^2 (6, n = 587) = 10.13, p>.05. This indicates that members with different community roles were just as like to belong to public communities as they were to private communities. Despite the fact that the relationship between community member role and participation in private vs. public communities was not found to be significant, a significant relationship between community member role and the posting of messages that contain social support provisions between public and private communities was found, χ^2 (6, n = 2,255) = 189.23, p<.05, indicating the posting of messages with social support by different genders varied by the openness of a community. Please see Tables 19 and 20.

Table 19: Frequency of Role Participation by Community Openness

	Openness	
	Public (n=93)	Private (n=494)
Unclassified	25%	15%
Patient	23%	37%
Spouse/Partner	16%	18%
Child of Patient	20%	17%
Parent of Patient	2%	2%
Other Family Member of Patient	10%	7%
Other	4%	3%
Total	100%	99%*

* Does not add up to 100% due to rounding error.
χ^2 (6, n = 587) = 10.13, p>.05.

Table 20: Frequency of Social Support by Role by Community Openness

	Openness	
	Public (n=272)	Private (n=1983)
Unclassified	7%	7%
Patient	19%	51%
Spouse/Partner	18%	18%
Child of Patient	14%	11%
Parent of Patient	1%	1%
Other Family Member of Patient	32%	9%
Other	9%	2%
Total	100%	99%*

* Does not add up to 100% due to rounding error.
χ^2 (6, n = 2,255) = 189.23, p<.05.

Finally, data indicate that a larger proportion of messages containing purely emotional support provisions were posted in private communities (60%) than in public communities (43%), while a larger proportion of messages containing purely information support were posted in public communities (43%)

than in private communities (29%). The relationship between openness and social support provision type was found to be significant, χ^2 (2, n = 2,255) = 29.44, p<.05, meaning that the types of social support messages in online cancer communities varied by community openness. Please see Table 21.

Table 21: Frequency of Social Support Type by Community Openness

	Openness	
	Public (n=272)	Private (n=1983)
Informational Support Only	43%	29%
Emotional Support Only	43%	60%
Both Informational and Emotional Support	13%	11%
Total	99%*	100%

* Does not add up to 100% due to rounding error.
χ^2 (2, n = 2,255) = 29.44, p<.05.

Post Volume

In terms of post volume, a significant relationship was found between gender and participation in communities with varying degrees of post volume, χ^2 (2, n = 587) = 7.35, p<.05, meaning that the demographic composite of community members in terms of gender varied by the post volume of a community. In addition, a greater proportion of females were found to have posted social support provisions in communities that had a high post volume, whereas males posted a greater proportion of messages with support provisions in communities with low post volumes. The differences in gender and the posting of support provisions by community post volume was found to be significant, χ^2 (2, n = 2,255) = 43.53, p<.05. Please see Tables 22 and 23.

Table 22: Frequency of Gender Participation by Community Post Volume

	Post Volume	
	Low (n=184)	High (n=403)
Males	18%	20%
Females	62%	68%
Unclassified	20%	12%
Total	100%	100%

χ^2 (2, n = 587) = 7.35, p<.05.

Table 23: Frequency of Gendered Social Support by Post Volume

	Post Volume	
	Low (n=484)	High (n=1,771)
Males	27%	19%
Females	62%	76%
Unclassified	11%	5%
Total	100%	100%

χ^2 (2, n = 2,255) = 43.53, p<.05.

In addition to the significant relationships between gender and community post volume, significant relationships were also found between community member role and participation in communities with varying degrees of post volume, χ^2 (6, n = 587) = 19.28, p<.05, and community member role and the frequency of posting messages that contain social support provisions in communities with varying post volume, χ^2 (6, n = 2,255) = 159.95, p<.05. This means that the demographic composite of community members in terms of role varied by community post volume and that the frequency of different community member role groups posting messages with social support also varied community post volume. Please see Tables 24 and 25.

Table 24: Frequency of Role Participation by Community Post Volume

	Post Volume	
	Low (n=184)	High (n=403)
Unclassified	23%	14%
Patient	38%	33%
Spouse/Partner	12%	20%
Child of Patient	12%	20%
Parent of Patient	3%	2%
Other Family Member of Patient	8%	8%
Other	5%	3%
Total	101%*	100%

* Does not add up to 100% due to rounding error.
χ^2 (6, n = 587) = 19.28, p<.05.

Table 25: Frequency of Social Support by Role by Community Post Volume

	Post Volume	
	Low (n=484)	High (n=1,771)
Unclassified	10%	6%
Patient	38%	50%
Spouse/Partner	13%	20%
Child of Patient	8%	13%
Parent of Patient	2%	1%
Other Family Member of Patient	20%	10%
Other	10%	1%
Total	101%*	101%*

* Does not add up to 100% due to rounding error.
χ^2 (6, n = 2,255) = 159.95, p<.05.

Finally, data indicate there was a greater proportion of messages containing purely emotional support provisions in the high post volume condition (63%) than there was in the low post volume condition (40%). Conversely, there was a greater proportion of messages containing purely informational support provisions in the low post volume condition (46%) than there was in the high post volume condition (26%). Results indicate that the differences between post volume and social support provision type are significant, χ^2 (2, n = 2,255) = 89.88, p<.05. This means that the types of social support messages in online cancer communities varied by community post volume. Please see Table 26.

Table 26: Frequency of Social Support Type by Community Post Volume

	Post Volume	
	Low (n=484)	High (n=1,771)
Informational Support Only	46%	26%
Emotional Support Only	40%	63%
Both Informational and Emotional Support	14%	11%
Total	100%	100%

χ^2 (2, n = 2,255) = 89.88, p<.05.

Community Size

Data indicate that no there was no significant relationship between gender and participation in communities of different sizes, χ^2 (2, n = 587) = 4.00, p>.05. This suggests that males and females were just as likely to belong to large communities as they were to small communities. Despite the lack of relationship between gender and membership in communities of different sizes, the relationship between gender and the frequency of posting messages that contain social support provisions in communities of different sizes was found to be significant, χ^2 (2, n = 2,255) = 58.95, p<.05. Please see Tables 27 and 28. Overall, males posted a larger proportion of messages with support provisions in small communities (28%) than they did in large communities (15%), whereas females posted a larger proportion of messages with support provisions in large communities (79%) than they did in small communities (65%).

Table 27: Frequency of Gender Participation by Community Size

	Community Size	
	Small (n=237)	Large (n=350)
Males	18%	21%
Females	65%	67%
Unclassified	18%	12%
Total	100%	100%

χ^2 (2, n = 587) = 4.00, p>.05.

Table 28: Frequency of Gendered Social Support by Community Size

	Community Size	
	Small (n=463)	Large (n=1650)
Males	28%	15%
Females	65%	79%
Unclassified	7%	6%
Total	100%	100%

χ^2 (2, n = 2,255) = 58.95, p<.05.

In addition to the significant relationships between gender and participation and posting of support provisions in communities of different sizes, significant relationships were also found between community member role and participation in communities of different sizes, χ^2 (6, n = 587) = 54.93, p<.05, as well as between community member role and the frequency of posting messages that contain social support provisions in communities of different sizes, χ^2 (6, n = 2,255) = 371.10, p<.05. This indicates that the demographic composite of community members in terms of role varied by community size as did the frequency of posting social support messages by different community member roles. Please see Tables 29 and 30.

Table 29: Frequency of Role Participation by Community Size

	Community Size	
	Small (n=237)	Large (n=350)
Unclassified	19%	15%
Patient	47%	26%
Spouse/Partner	10%	23%
Child of Patient	9%	23%
Parent of Patient	4%	1%
Other Family Member of Patient	6%	9%
Other	5%	3%
Total	100%	100%

χ^2 (6, n = 587) = 54.93, p<.05.

Table 30: Frequency of Social Support by Role by Community Size

	Community Size	
	Small (n=149)	Large (n=1,067)
Unclassified	5%	8%
Patient	66%	33%
Spouse/Partner	7%	26%
Child of Patient	4%	17%
Parent of Patient	2%	.2%
Other Family Member of Patient	10%	14%
Other	5%	2%
Total	100%	100%

χ^2 (6, n = 2,255) = 371.10, p<.05.

Finally, data indicate that there was no significant relationship between community size and the frequency of postings with strictly emotional support provision, strictly informational support provision, and postings with both types of support provision, χ^2 (2, n = 2,255) = 1.98, p>.05. This indicates that each type of social support provision was just as likely to appear in small vs. large communities. Please see Table 31.

Table 31: Frequency of Social Support Type by Community Size

	Community Size	
	Small (n=968)	Large (n=1,287)
Informational Support Only	29%	31%
Emotional Support Only	60%	57%
Both Informational and Emotional Support	11%	12%
Total	100%	100%

χ^2 (2, n = 2,255) = 1.98, p>.05.

H1: Gender in Online Support Communities

The first hypothesis in this investigation was a multipart hypothesis dealing with the gender of participants in online support communities. The first part of this hypothesis stated:

- *H1a: There will be a larger proportion of women in the online support communities than men.*

During the sample period, as mentioned previously, there were 587 unique community members who posted messages in the eight different communities. The majority of each community was made up of females. Of the 587 unique community members, 389 were female (66%), 114 were male (19%), and 84 were unclassified (14%), thus supporting hypothesis 1a. Table 32 provides a complete breakdown of the gender of unique posters by community. Significant differences were found between gender and community membership indicating that these two variables are significantly related, χ^2 (14, n = 587) = 40. 65, p<.05.

Table 32: Frequency of Gender across Communities

	Gender		
	Male (n=114)	Female (n=389)	Unclassified (n=84)
Yahoo: Melanoma	11%	5%	14%
Yahoo: Thyroid Cancer	8%	10%	6%
Yahoo: Pancreatic Cancer	5%	7%	17%
Yahoo: Lung Cancer	18%	23%	31%
ACOR: Melanoma	6%	4%	5%
ACOR: Thyroid Cancer	7%	13%	8%
ACOR: Pancreatic Cancer	26%	17%	6%
ACOR: Lung Cancer	19%	21%	13%
Total	100%	100%	100%

$\chi 2$ (14, n = 587) = 40.65, p<.05.

The second part of this multifaceted hypothesis stated that:

- *H1b: Women will post more messages than men.*

Results indicate that in addition to making up the majority of unique posters, females also posted the majority of the posts during the sample period, as well as the majority of messages containing social support. Out of the total sample, 2,689 messages (72%) were posted by females, 799 messages (21%) were posted by males, and 229 (6%) were posted by community members whose gender was unclassified, thus supporting hypothesis 1b. Significant differences were found in the number of messages containing social support provisions posted by males, females, and individuals whose gender was unclassified across the different communities, χ^2 (14, n = 2,255) = 218.08, p<.05. Table 33 provides a complete breakdown of the total number of messages that included social support provisions posted in each community by gender.

Table 33: Frequency of Gendered Social Support by Community

	Gender		
	Male (n=463)	Female (n=1,650)	Unclassified (n=142)
Yahoo: Melanoma	8%	2%	10%
Yahoo: Thyroid Cancer	30%	20%	11%
Yahoo: Pancreatic Cancer	11%	7%	21%
Yahoo: Lung Cancer	7%	31%	27%
ACOR: Melanoma	3%	2%	1%
ACOR: Thyroid Cancer	8%	8%	4%
ACOR: Pancreatic Cancer	15%	15%	3%
ACOR: Lung Cancer	19%	16%	23%
Total	101%*	101%*	100%

* Does not add up to 100% due to rounding error.
χ^2 (14, n = 2,255) = 218.08, p<.05.

The third and fourth parts of this hypothesis stated:

- *H1c: Women will provide a greater proportion of emotional support than men.*
- *H1d: Men will provide a greater proportion of informational support than women.*

Regarding social support provision, data indicate that both males and females provided a greater percentage of purely emotional support (51% and 61% respectively) than purely informational support (35% and 28% respectively) or informational and emotional support combined (14% and 11% respectively). Those whose gender was unidentified provided a greater percentage of purely informational support (48%) than purely emotional support (43%) or combined informational and emotional support (9%). Please see Table 34 for a complete for a complete breakdown of social support provisions by gender.

Despite the fact that emotional support provisions were given more frequently by males and females, females provided a greater percentage of emotional support (61%) than did males (51%) or the unclassified group (43%). The group providing the largest percentage of purely informational support were those people whose gender was unclassified (48%) as compared to males (35%) and females (28%). When looking only at males and females, males tended to provide a greater proportion of informational support than females and females tended to provide a greater proportion of emotional support than males. Results indicate that these differences were significant, χ^2 (4, n = 2,255) = 37.32, p<.05, thus supporting hypotheses 1c and 1d.

Table 34: Frequency of Social Support Type by Gender

	Gender		
	Male (n=463)	Female (n=1,650)	Unclassified (n=142)
Informational Support Only	35%	28%	48%
Emotional Support Only	51%	61%	43%
Both Informational and Emotional Support	14%	11%	9%
Total	100%	100%	100%

χ^2 (4, n = 2,255) = 37.32, p<.05.

H2 and H3: Social Support Provision by Five-Year Survival Rate

Based on Optimal Matching Theory, the final two hypotheses in this investigation dealt with social support provision types in communities for varying five-year survival rates. These hypotheses stated:

- *H2: There will be a greater proportion of emotional support provision in communities for cancers with low five-year relative survival rates as* *opposed to communities for cancers with high five-year relative survival rates.*

- *H3: There will be a greater proportion of informational support provision in communities for cancers with high five-year relative survival rates as opposed to communities for cancers with low five-year relative survival rates.*

Results indicate that the majority of messages that included social support provisions in this sample were from communities for low-five-year relative survival rate cancers (66%) as opposed to the high five-year relative survival rate cancers (34%). Results show that both high and low survival rate communities had a greater percentage of emotional support as opposed to informational support or combinations of emotional and informational support. Despite this fact, counter to hypotheses two and three, the low five-year relative survival rate communities were found to have a larger percentage of purely informational support (33%) than the high five-year relative survival rate communities (25%) and the high five-year relative survival rate communities had a larger percentage of purely emotional support (65%) than the low five-year relative survival rate communities (54%). Please see Table 35.

Data indicate the differences in the five-year relative survival rate and the frequency of postings with strictly emotional support provision, strictly informational support provision, and postings with both types of support provision were significant, χ^2 (2, n = 2,255) = 21.78, p<.05, therefore H2 and H3 were not supported.

Table 35: Frequency of Social Support Type by Survival Rate

	Five-Year Relative Survival Rate	
	Low (n=1483)	High (n=772)
Informational Support Only	33%	25%
Emotional Support Only	55%	65%
Both Informational and Emotional Support	12%	11%
Total	99%*	101%*

* Does not add up to 100% due to rounding error.
χ^2 (2, n = 2,255) = 21.78, p<.05.

Summary

In summary, results from this investigation indicate that social support provisions are common as they were present in 60% of the posted messages during this sample period. Regarding our research questions, community member role, five-year survival rate, and community characteristics such as community host, openness of the community, community post volume, and community post size were, for the most part, all found to have interesting relationships with participation in communities, the posting of messages with social support provisions, and the types of social support provided within online support communities. In addition, although support was found for the first hypothesis as females were found to make up the largest demographic of online community members, post the most messages, and provide a larger proportion of emotional support than males, while males post a larger proportion of informational support than females, no support was found for hypotheses two and three that stated there would be a larger proportion of emotional support provisions in low survival rate communities and a larger proportion of informational support provisions in high survival rate communities. Next, chapter five presents a more in-depth discussion of the pertinent research findings.

Chapter 5: Discussion

At the outset, this investigation sought to investigate online support communities for cancers with high and low five-year relative survival rates. In addition to understanding who is utilizing these communities in terms of gender and community member role, this study also sought to understand the different types of social support provisions that are occurring within these online spaces. The purpose of this final chapter is to more fully explain the major findings from this investigation as outlined in the previous chapter.

Overall, findings from this investigation indicate that social support provisions are abundant within online support communities for cancers with high and low five-year survival rates. While females make up the largest demographic in these online communities, males actively participate as well. Results indicate that the first hypothesis regarding gender in online communities was supported as females make up the largest demographic of online community members, post the most messages, and provide a larger proportion of emotional support than males, while males post a larger proportion of informational support than females. Unfortunately, no support was found for hypotheses two and three that stated there would be a larger proportion of emotional support provisions in low survival rate communities and a larger proportion of informational support provisions in high survival rate communities.

This investigation also found that community member role was significantly related to social support provision as patients and immediate family members tended to provide more emotional support, while other family members and individuals classified as "other" provide more informational support. Furthermore, significant relationships between role and the participation in high and low five-year relative survival rates were found as well between role and the posting of messages with social support provisions in high and low five-year survival rate communities.

In terms of characteristics of communities that impact online support groups, this investigation found that the public or private nature can have significant effects on the types of social support provision within online support communities as emotional support seems to be provided in larger proportion in private communities and informational support is presented in larger proportions in public communities. It was also found that there were very real differences between social support provision types for the two community hosts. Finally the post volume of a community was found to impact the gender and social support provisions of online community members and the size of the community was found to impact gendered participation.

In this chapter, these pertinent findings are highlighted along with a discussion regarding possible explanations for the results, as well as an assessment of the importance of the findings and their implications. Following the discussion of the research findings, the limitations of this study are presented along with a discussion of future directions for research.

Social Support Provision within Online Support Communities

Results from this investigation indicate that social support provisions are quite common within online support communities for cancers with high and low five-year relative survival rates. Data indicate that overall, social support provisions were present in 60% of the sample. When looking at all eight communities individually, it was found that the percentage of messages that contained social support provision within a particular community during the sample period ranged from 49% – 72%. Regarding the type of social support provision, emotional support was by far the most prevalent as 58% of the messages that contained social support provision only contained instances of emotional support and 30% of messages with social support provisions contained only informational support provisions. Interestingly enough, only 11% of messages with social support provisions contained instances of both informational and emotional support.

The fact that social support provisions are so prevalent within online support community messages is unsurprising as this is presumably why many people turn to online support groups. People who are not interested in receiving and/or providing social support would not necessarily belong to an online support group in the first place. This finding indicates that online social support groups are efficaciously performing one of their fundamental objectives: to provide social support.

The finding that social support provisions are prevalent within online support communities is important since it indicates that online support communities are fulfilling their purpose. These online communities are places where people go to provide and receive social support. This has great implications for the marketing of online social support communities for cancer from both the online community and the healthcare provider perspectives. Finding that online support communities really do provide social support is of great benefit to the online communities themselves as it may be a springboard for marketing online services to the general public and the healthcare community. In addition, if healthcare providers are confident that online support communities actually do provide necessary emotional and informational support to community members, they may be more prone to recommending that individuals utilize these groups for social support. Particularly for patients who may have small support networks or may live in locations where offline support groups are not available, there are many reasons why a healthcare provider may recommend that patients join an online support group, even if it is just to lurk and read archived postings.

Gender and Online Support Communities

At the outset of this investigation, a multipart hypothesis was created stating that based on the literature concerning social support and gender, there would be a larger proportion of women in the online support communities than men, women would post more messages than men, women would provide a greater proportion of emotional support than men, and that men would provide a greater proportion of informational support than women. Data provided support for all four parts of this multifaceted hypothesis.

Based on previous research suggesting women are more likely to join traditional offline support groups (Krizek et al., 1999) and that current members of traditional support groups are more likely to be female (Grande et al., 2006;

Moos et al., 2006), it was expected that women would participate in online support groups more frequently than men. Of the 587 unique community members who posted messages in the eight online support communities during the sample period, 66% were women, 19% were men, and 14% were unclassified. As those community members identified as women made up two-thirds of the unique community members included in this investigation, our expectation that the majority of community members would be female was met. Clearly, like in traditional offline support groups, men are less likely to participate in online support groups. While we are unable to draw conclusions as to why men participated in online support communities less frequently than women, it is possible that as previous research suggests, they do rely more on their spouses for support and less on sources outside the home.

In addition to the fact that women currently make up the largest percentage of online support community members, the multipart hypothesis concerning gender also stated the expectation that women would also post the majority of messages within online support groups. This expectation was met as out of the 3,717 messages included in this sample, 72% were written by females, 21% were written by males, and only 6% were written by individuals whose gender was unclassified. This finding supports the conclusion that women provide social support more often than men as indicated by previous research (Belle, 1982; Fischer, 1982; Griffith, 1985; Kendler et al, 2005; Kessler et al., 1985; Trobst et al., 1994). If the members of an online support community are viewed as members of a social network, this finding also supports the conclusion that women are more involved in their social networks (Kendler et al., 2005; Rosenthal et al., 1986).

The final two parts in our multipart hypothesis relating to gender indicated that it was expected that women would provide a greater proportion of emotional support than men, whereas men would provide a greater proportion of informational support than women. These expectations were based on previous research indicating that women are more likely than men to provide emotional support and men are more likely than women to provide informational support (Klemm et al., 1999; Rosenthal et al., 1986; Seale et al., 2006; Sullivan, 2003). Results indicate that both of these expectations were met as a larger proportion of men (35%) provided instances of purely informational support than did women (28%) and a larger proportion of women (61%) provided purely emotional support than did men (51%). It did come as a surprise though that both genders provided a greater proportion of purely emotional support than purely informational support. These findings suggest that within online support communities, regardless of gender, emotional support provisions are far more common.

The finding that women are more active within online support groups has very practical implications for the design of online support communities. Although we are unable to ascertain exactly why women participate more in both online and offline support groups than men, it is possible that either men do not see as much value in support groups and choose not to participate in them, or it is possible that the overwhelming presence of women may discourage more frequent participation from men. Additionally, it could also be that men are socialized over their lives to not seek out support in social ways. Because we are unable to see what the demographics of the lurkers are, it is also possible that men may actually frequent online support communities as often as women, but they may choose not to actively participate. Overall, these findings related to gender possibly speak to the need to solicit more males to actively participate within online support communities. This could be done through the creation of online support groups specifically for men. Or, it is possible that if the men who are currently involved in online support communities become more active, more men may be encouraged to participate. Through the encouragement of active male participation in online support communities, other men seeking social support may benefit due to the fact that there would be more people that they could relate to providing social support.

Five-Year Survival Rate and Social Support Provision

Overall, emotional support was provided more frequently than informational support in both high and low five-year survival rate communities. The fact that emotional support was more prevalent in both high and low survival rate communities suggests that there are more people providing emotional support in online communities than informational support. Reasons for why there is more emotional support rather than informational support is unclear, although it is possible that either online support community members go elsewhere to obtain information, online community use lends itself to be more effective for emotional support, or perhaps there are more instances of emotional support because when a person requests emotional support, more people respond to comply, whereas when a person requests informational support, when the information is given, there is no need for community members to continue to respond.

In this investigation, as indicated by the second and third hypotheses, it was expected that five-year survival rate would significantly affect social support provision. Based on Optimal Matching Theory, using five-year relative survival rate as a proxy for controllability, it was hypothesized that there would be a greater proportion of emotional support provisions in low five-year survival rate communities than in high five-year survival rate communities. It was further hypothesized that there would be a greater proportion of informational support provisions in high five-year survival rate communities than in low five-year survival rate communities.

Contrary to the stated hypotheses, low five-year survival rate communities contained a greater proportion of purely informational support (33%) than the high five-year survival rate communities (25%) and high five-year survival rate communities contained a greater proportion of purely emotional support (65%) than did the low five-year survival rate communities (55%). This indicates that there was no support for hypotheses two and three, although the relationship between social support type and five-year relative survival rate was found to be significant, meaning that the assumption of a relationship between social support provision and five-year relative survival rates was correct, but the direction of the relationship was incorrect.

Possible reasons to explain why hypotheses two and three were not supported include the idea that while Cutrona was correct in asserting a relationship between controllability and social support provision type in Optimal Matching Theory, she misunderstood the nature of the relationship. Data from this investigation suggest that while controllability (in this case, survival rate) is significantly related to social support provision, informational support is provided in greater proportion in low survival rate communities than in high survival rate communities, while emotional support is provided in greater proportion in high survival rate communities than in low survival rate communities. It is possible that in low survival rate situations, people experiencing low five-year survival rate cancers are desperate for information as opposed to those people experiencing high five-year survival rate cancers. Furthermore, in high five-year survival rate situations, it is possible that emotional support is provided in greater proportion than in low five-year survival rate conditions because information isn't as necessary or perhaps because these individuals are more hopeful for a positive outcome.

Another possible explanation for the fact that no support was found for hypotheses two and three relates to the idea of individual self-efficacy. It is possible that individuals experiencing high survival rate cancers have higher levels of self-efficacy in regards to dealing with cancer and feel less of a need for informational support, whereas individuals experiencing low survival rate cancers have lower levels of self-efficacy when dealing with cancer and need more informational support.

These findings speak to the need for medical professionals to provide copious amounts of information to patients who have been diagnosed with a low survival rate cancer and their families. While emotional support is vital for any type of cancer diagnosis, there seems to be a greater need to provide informational support during these low survival rate situations, than in high survival rate situations. In addition, these findings also suggest that online support communities for low five-year survival rate cancers would benefit from having informational resources that community members could utilize. Whether these informational resources take the shape of FAQ pages located on the community homepage, links to external websites, links to specific message postings that were particularly informative, or even a collaborative informational document such as a wiki, easily accessible informational sources could be quite beneficial to all community members, particularly new members just joining a community.

Community Member Role and Social Support Provision Type

Results from this investigation indicate that there is a significant relationship between community member role and social support provision type. Data indicate that patients and their immediate family members (spouses/partners, children of patients, and parents of patients) all provided larger proportions of purely emotional support than they did purely informational support. Conversely, those community members who were not immediate family members (classified as other family members of patients or "other") provided larger proportions of purely informational support.

One possible explanation for the finding that patients and immediate family members provide a greater proportion of purely emotional support as opposed to purely informational support stems from the notion that these individuals may be better able to provide emotional support due to their trials and tribulations of dealing with cancer. As these individuals are experiencing cancer either themselves or through an immediate family member, they may better understand the emotional experiences involved with cancer and be better suited to provide emotional support. Family members who are not immediately related to patients and those people classified as “other” may not be as well equipped to provide emotional support because they are farther removed from the cancer experience. Therefore, individuals who are not patients or immediate family members may be best suited to providing informational support to others.

The finding that patients and immediate family members of cancer patients provide a greater proportion of emotional support than informational support is important in that it indicates that there may be a need to encourage family members not in a patients’ immediate family, as well as individuals classified as “other”, to provide emotional support to others, particularly those in similar situations. One of the benefits of online support communities is that individuals can connect with others in similar situations. While patients are providing emotional support in abundance, it could be beneficial for non-immediate family members and those classified as “other” to receive social support provisions from other individuals with the same role. If non-immediate family members and those individuals classified as “other” are not providing a great frequency of emotional support, individuals in similar situations looking for emotional support from people with similar experiences may be lacking the social support that their counterparts could provide.

Community Member Role and Five-Year Relative Survival Rate

Another interesting finding from this study was that despite the fact that patients make up the largest proportion of unique community members from low five-year relative survival rate communities (58%) and do not necessarily make up a significantly large proportion of the high survival rate communities, they by far provide the largest proportion of messages containing social support provisions in high five-year survival rate communities (82%).

This finding could possibly be explained by the idea that in high survival rate communities, patients are considered to be the authority on the specific type of cancer, thus are more qualified to provide social support as they have coped with the illness and most likely have a good prognosis. In low survival rate communities, it is possible that patients are not considered the authority and that spouses, family members, and individuals with other roles may also be viewed as being equally qualified to provide social support. It is also possible that perhaps patients in low survival rate communities are just sicker than patients in high survival rate communities and are thus too ill to post more often.

This finding has great implications in that it suggests that it may be essential to develop online support communities for high survival rate cancers that are specifically oriented to non-patients. Again, one benefit of online support communities is that they provide people with an opportunity to connect with others in similar situations. When patients provide the bulk of support provisions in communities for cancers with high five-year survival rates, those members who are not patients may miss out on valuable insights that other non-patients could possibly provide. By creating online communities specifically for individuals who are not patients, we may be able to foster more activity from this group.

Impact of Openness on Online Support Communities

Another interesting finding from this investigation is that there is a significant relationship between the openness of a community and the posting of messages containing social support provisions from males and females. Results indicate that males post a larger proportion of messages with social support provisions in public communities (31%) than in private communities (19%). Conversely, women post a larger proportion of messages with social support provisions in private communities (76%) than in public communities (53%).

Data also indicate that there is a significant relationship between openness and the types of social support provided in messages. Results show that a larger proportion of messages with purely informational support are posted in public communities (43%) as opposed to private communities (29%), whereas a larger proportion of messages with purely emotional support are posted in private communities (60%) as opposed to public communities (43%).

The most intuitive explanation for the differences in social support provision type as it relates to community openness is that people are more comfortable posting personal, emotional support provisions in private spaces and that informational support lends itself to public spaces where the information will reach a broader audience. Unfortunately, due to the limitations of the utilized methodology, it is impossible to tell whether or not this is the case. An alternative explanation for the patterns found in gendered posting by public and private communities could be that women are potentially more comfortable posting messages in an environment where they know that there is a greater level of privacy while men are more comfortable in a public environment.

To explain social support provision types as they occur in public vs. private communities, it is possible that there is a larger proportion of purely emotional support provision in private communities because women (who tend to post emotional support provisions) post most frequently in private communities. Likewise, it is possible that there is a larger proportion of purely informational support provision in public communities because men (who tend to post informational support provisions) post most frequently in public communities. While this doesn't explain why men and women tend to post where they do, it is a reasonable explanation as to why the types of support are found in communities based on openness.

The finding that there is a significant relationship between community openness and the posting of social support provisions has great implications for the design of online support communities. Clearly, the openness of a community has a very real effect on the types of messages that people post. The decision to leave a community public or make it private should not be taken lightly. Findings from this investigation suggest that when trying to develop a support group for emotional support, the community should be made private, whereas when trying to develop a support community for the purposes of informational support, it is possible that the community could benefit from being left public.

Community Host and Social Support Provision

Data reveal that there is a significant relationship between community host and social support provision type. Specifically, there is a greater proportion of purely informational support provision in the ACOR communities (45%) than in the Yahoo! communities (21%) and there is a greater proportion of purely emotional support provision in the Yahoo! communities (69%) than in the ACOR communities (42%).

This relationship could be possibly explained by the very different nature of the two community hosts. As mentioned in chapter three, ACOR is a community host specifically intended for cancer-related purposes. When people visit ACOR, they do so in order to find cancer-related information and social support. On the other hand, Yahoo! is a community host that is not cancer-specific. People who join online cancer support communities through Yahoo! may already utilize other Yahoo! based communities or web-based services for a variety of different reasons. It is quite possible that a greater proportion of informational support provisions were found in ACOR communities as opposed to Yahoo! communities because there is a greater expectation that informational support will be available through ACOR. This could be due to perceptions that people at ACOR have more expertise with cancer and are more qualified to provide informational support versus the people at Yahoo! If this in fact were the case, as social support provisions are ideally matched to social support seeking, it makes sense that there would be more informational support seeking at ACOR and therefore more informational support provisions. As there may potentially be a lack of perceived expertise at Yahoo! communities, it also makes sense that there would be less informational support seeking and therefore a greater frequency of emotional support provisions in these communities.

The finding of the significant relationship between community host and social support provision has many implications for the use of online support communities. If in fact there is a greater proportion of informational support at ACOR due to its cancer-specific nature, this implies that those individual who are seeking informational support would be best served joining a cancer-specific community. If this finding were to apply to all communities, cancer-specific community hosts would be best served by marketing the frequency and quality of informational support provision available to their members. In addition, healthcare providers would be best served to steer new patients to cancer-specific communities when looking for informational support.

Post Volume, Gender Participation, and Social Support Provision

Data from this investigation indicate that females post a larger proportion of messages containing social support provision to communities that have a high post volume (76%) as opposed to a low post volume (62%), whereas males post a larger proportion of messages to communities with a low post volume (27%) as opposed to a high post volume (19%).

This finding could possibly be explained by suggesting that males are more comfortable posting in small volume communities, whereas females are more comfortable posting in large volume communities. This possible explanation potentially has merit as previous research has indicated that women tend to have larger support networks than men (Antonucci & Akiyama, 1987; Belle, 1987; Fischer, 1982; Turner, 1994) and therefore may be more comfortable contributing to communities that have larger volumes of posts.

Data also indicate that there is a larger proportion of purely emotional support in high post volume communities (63%) as opposed to low post volume communities (40%), while there is a larger proportion of purely informational support in low post volume communities (46%) as opposed to high post volume communities (26%). A possible explanation for this finding is that the number of emotional support provisions may create high post volume communities due to the fact that one specific request for emotional support elicits multiple emotional support provisions from different community members. On the other hand, the number of informational support requests may create low volume communities because one specific request for informational support from a community member may only elicit a small number of responses due to the fact that once one person has provided the necessary information, there is no need for others to keep responding.

It is also possible that the differences in post volume could be due to the posting patterns of the different genders. As males post more often in low post volume communities and they tend to provide informational support more often than emotional support, this could possibly explain why there is more informational support provision in low post volume communities. Conversely, as females post more often in high post volume communities and they tend to provide emotional support in a greater proportion than informational support, this could explain why there is more emotional support provision in high post volume communities.

If in fact there are fewer informational support provisions in low post volume communities due to the fact that informational support only really requires a small number of support provisions to satisfy someone seeking informational support, this speaks to the notion that online support communities, regardless of post volume, should have an informational resource that community members can utilize to answer basic questions regarding the specific disease and illness. As mentioned previously, whether this informational resource takes the shape of a FAQ page located on the community homepage, links to external websites, links to specific message postings that were particularly informative, or even a collaborative informational document such as a wiki, this type of informational source could be quite beneficial to all community members.

Contributions from this Study

Results from this investigation are important as they give us very real prescriptive suggestions as to how online support communities should be structured for various circumstances. As research in the field of online support communities has been largely descriptive in nature, this investigation begins to allow for the understanding of how issues such as the demographics of community members and the characteristics of a community can have real life impacts on the types of social support provisions that are found online. This can have real life consequences as the community members who utilize these services have very real support needs since they are dealing with cancer either themselves or through a family member or friend. When dealing with online support communities, researchers need to understand that we are dealing with people's lives and potentially their health. It is through further investigations such as this that we will be better able to understand how support communities should be designed to more effectively help the community members who are utilizing them.

This investigation also contributes to the existing body of literature pertaining to online support communities as it marked the creation of a reusable coding protocol. Aside from those communities focused on cancer, this coding protocol could be used to evaluate social support provisions in a variety of health-related online support communities.

Regarding theoretical contributions, this investigation adds to Optimal Matching Theory by upholding the idea that controllability has a significant relationship with the type of social support provided. In the original papers on Optimal Matching Theory, as previously indicated, Cutrona specified that emotional support was more important in low controllability circumstances, serving as the basis for the predictions that emotional support messages would be more prevalent in low survival rate communities than in high survival rate communities and informational support messages would be more prevalent in high survival rate communities than in low survival rate communities. This investigation adds to OMT through the finding that theses hypotheses were not supported, and that at least in online support groups, emotional support is provided in greater frequency in both low and high controllability conditions. This suggests that either there are more messages within online support communities that elicit emotional support responses or that there is something about emotional support seeking that elicits more responses than informational support seeking within online communities. In addition to adding to OMT though increasing our understanding of how controllability is related to social support provision, this investigation adds to OMT by demonstrating its use in an electronic environment.

Limitations

As with all research investigations, this study is not without limitations. Perhaps the largest limitation to this investigation is the fact that this study was strictly a content analysis of posted messages within the eight online support communities for cancers with high and low five-year survival rates. Due to the limitations of content analysis, this study does not provide a deeper understanding of peoples' motivations to participate and provide social support within online support communities.

A second limitation of this investigation is that while social support provisions were captured, it is unclear whether the support that was provided was viewed as useful and beneficial by the support recipient. Again, due to the limitations of content analysis, this was not possible. Also, because this investigation excluded any sources of social support outside of the online communities (i.e., in emails, over the phone, in person, etc.), this investigation only captured a narrow slice of the total social support available to an individual.

Another limitation of this study relates to the fact that as this investigation did not focus at all on social support seeking, no conclusions can be made as to how frequently social support is actually sought. In addition, the fact that this study did not tie online support community use to actual health outcomes is another limitation of this investigation.

Finally, a limitation of this investigation is that no direct quotations were reported. Direct quotations would have enriched the results section of this study as they could have been used to fully demonstrate how different types of emotional support and informational support actually appear within online support communities. This limitation was a direct result of the restrictions placed by the institutional review board at Michigan State University.

Despite these limitations, this study still is meaningful and important in that steps have been taken to move beyond descriptive case study analysis of individual support communities. This investigation serves as the first step in a long line of research that aims to not only improve the quality of research in this field, but seeks to understand what can be done to more effectively support the social support needs for different types of people as they experience cancer.

Future Research

As with any research investigation, results from this study raise a whole host of new and interesting questions regarding social support within online health-related communities. Since this investigation served as the foundation for what will no doubt become a long line of research involving online health-related communities, these questions will help to focus the future direction of this research stream.

To begin with, this investigation revealed differences in the types of social support provided within public and private communities. Future work should focus on better understanding why people choose to participate in public and/or private communities, how the level of openness impacts community demographics, and why there are differences between social support interactions within these public and private spaces. Because the decision to make an online support community public or private has potentially significant consequences for the interactions that occur within online communities, this decision should not be made lightly and the more researchers can understand the implications of community openness, the better off online communities will be.

Next, this investigation indicated that people with different demographics (regarding both gender and community member role) had fundamental differences in the types and frequency of social support messages that were provided. Future work should seek to understand why different sources provide different types of social support. By better understanding why different sources provide the types of social support that they do, health-related services may be better able to design effective resources for different types of people.

Although this investigation provided much data concerning the frequency of social support messages, no data concerning the quality of emotional or informational support was of obtained or analyzed. As the quantity vs. quality issue is of vital importance when dealing with peoples' health and quality of life, future work should seek to include measures of social support quality. In addition, future work should focus on the entire support process as it occurs online by studying social support seeking in conjunction with the provision of social support. For example, future work should seek to address how frequently social support is sought and how often responses with social support messages are provided. By more fully understanding the social support process within online support communities, we may be better able to provide effective and efficient support services both online and offline.

Finally, future work in this field should attempt to tie online support community use to actual health outcomes. If we truly wish to understand the impact of online social support communities within the health context, understanding how the social support that is received within an online environment impacts the actual health outcomes of community members is a must.

Appendix A: Vaux's Categories of Social Support Measures and their Respective Instruments

Measure of Support Network Resources	Measures of Supportive Behavior	Support Appraisals	Support Incidents	Help Seeking and Support Mobilization	Social Participation
Social Network Questionnaire (SNQ)	Inventory of Socially Supportive Behavior (ISSB)	Arizona Social Support Interview Schedule (ASSIS)	Social Support Incidents (SSI)	Efficacy of Help Seeking (EHS)	Community Support
Social Relationship Scale (SRS)	Social Support Behaviors (SSB)	Social Support Resources (SSR)		Network Orientation Scale (NOS)	
Social Support Questionnaire (SSQ)		Social Relationship Scale (SRS)			
Social Support Network Interview (SSNI)		Daily Interaction Rating Form (DIRF)			
Arizona Social Support Interview Schedule (ASSIS)		Social Support Questionnaire (SSQ)			
Social Support Resources (SSR)		Perceived Social Support (PSS)			
		Family Relationship Index (FRI)			
		Work Relationship Index (WRI)			
		Interpersonal Support Evaluation List (ISEL)			
		Social Provisions Scale (SPS)			
		Provision of Social Relationships (PSR)			
		Revised Kaplan Scale (RKS)			
		Social Support Appraisals (SSA)			

Appendix B: Coding Protocol

Introduction

This investigation seeks to identify the types and amounts of social support provisions contained within and across different cancer-related online support communities. For the purposes of this investigation, a content analysis will be conducted on posts from eight different cancer-related online communities; four hosted by Yahoo!Groups and four hosted by the Association of Online Cancer Resources (ACOR). These eight communities are focused on four different types of cancer, two that have high five-year relative survival rates (melanoma and thyroid cancers) and two that have low five-year relative survival rates (pancreatic and lung cancers). In our sample, we will be investigating one community focused on each type of cancer located in both Yahoo!Groups and ACOR. The URLs to the communities are as follows:

Yahoo!Groups:

- Melanoma http://health.groups.yahoo.com/group/melanoma/
- Thyroid Cancer http://health.groups.yahoo.com/group/thyroid-cancer/
- Pancreatic Cancer http://groups.yahoo.com/group/pancreatic_cancer/
- Lung Cancer http://health.groups.yahoo.com/group/Lung_Cancer_Support/

ACOR:

- Melanoma http://listserv.acor.org/archives/melanoma.html
- Thyroid Cancer http://listserv.acor.org/archives/thyroid-onc.html
- Pancreatic Cancer http://listserv.acor.org/archives/pancreas-onc.html
- Lung Cancer http://listserv.acor.org/archives/lung-nsclc.html

This protocol outlines a set of systematic procedures to be used in the coding of posted messages. Definitions and examples of all variables to be coded are included. The units of observation and the units of analysis in this investigation are individual community postings. Each post will be evaluated against the coding protocol. The following procedures may be applied to evaluate postings from any online health-related support community.

Conceptual Definitions

Online Community

An online community is conceptualized as collections of more than one person existing over a sustained period of time that have interdependence among one another in terms of common goals, interests, and/or identities. These collections of people must possess at least one channel of communication (in this case, the Internet) that can be used for the exchange of communication regarding their mutual goals, interests, identities, or interdependencies.

Functionally, we will consider online communities to be any combination of listservs, newsgroups, bulletin boards, message boards, chat groups, instant message systems, or web based portals on the Internet where people go to give/receive social support and/or information from other community members on a particular topic. These are the commonly accepted forms of online communities. Online communities are characterized by archives of posts which may or may not be publicly accessible.

Messages postings

Message postings are defined as individual posted messages, posted by one person, located within an online community. Although messages can only be posted by an individual person, they may be written on behalf of several people. A message posting can range in length from one word to several pages of communications. Postings may include text and in some cases even images. It is not uncommon for previous content to be copied in to messages, particularly when a person replies to a specific message. For the purposes of coding, only new content (not content copied from previous messages) will be analyzed for each post. Although not always, old content is typically designated with a "<" symbol at the beginning of a line. In circumstances where new responses are embedded within old content, only the new responses will be coded. Also, content that is a part of a subject or signature line will not be coded. Signature lines are considered to be closing words or phrases stated immediately before a persons name or alias. Examples include "sincerely", "yours", "best regards", "in God's name", "peace be with you", etc.

Controllability

In this investigation, five-year relative survival rates serve as a proxy for controllability. Controllability is conceptualized as the degree to which a particular disease or condition can be managed. For the purposes of this investigation, controllability is predetermined through the selection of online communities to be investigated. Communities were selected along varying levels of controllability. Therefore, coders do not need to code messages for controllability.

Gender

Gender is a social construct used to describe the self identified masculinity or femininity of a person. In this investigation, gender will be operationalized into two nominal categories based on sex; male and female. Because posters will most likely not self-identify their gender, gender will only be coded when it is contextually identified. Contextual cues to a person's gender may include discussion of being a mother or father, discussion of a spouse, etc. After coding is complete, coders will go back and "fill in the blanks" by matching gender with individual posters. If a poster never self-identifies their gender, they will be designated as unclassifiable.

Role of community member

The role of a community member is defined as the relationship an individual has to the community topic. For the purpose of this investigation, community role will be operationalized as a nominal level variable with values such as patient, caregiver, medical professional, or a friend or family member of patient. Because posters will most likely not self-identify their role in each post they write, roles will only be coded when they are identified. After coding is complete, coders will go back and "fill in the blanks" by matching self-identified roles with individual posters. If a poster never self-identifies their community role, they will be designated as unclassifiable. In the event that a person is coded as two different roles, one of which is a patient, the patient categorization will "trump" all other community member roles.

Social support

Social support encompasses the notion that that there are stressors in life and people may receive from others either the perception that assistance is or could potentially available or actual exchanges of emotional or instrumental assistance in times of need. These coding procedures for the presence of social support could be applied to any online support community, not just the eight being evaluated in this investigation. Each posting will be read and evaluated for the presence or absence of each of the different subtypes of social support. Because we are only interested in the total number of messages that each type of social support is present, each type of social support will only be counted once per message. For our purposes, we are only interested in the presence or absence of each subtype of social support. While a particular message may contain three different instances of support type A and two instances of support type B, we are only interested in the fact that the particular message contained support types A and B, not the overall instances of A and B.

Variable Definitions and Coding Information

Demographic and Administrative Variables (Variables 1 – 9)

V1. **Posting identification number -** This is the unique number assigned to each individual posting by the host community.

V2. **Cancer Type**
0 = Melanoma
1 = Thyroid
2 = Pancreatic
3 = Lung

V3. **Community Host**
0 = Yahoo!Groups
1 = ACOR

V4. **Openness**
0 = Public
1 = Private

V5. **Post Volume**
0 = Low
1 = High

V6. **Community Size**
0 = Small
1 = Large

V7. **Username of the message poster** – As found in the header information

V8. **Gender of the message poster** – As identified by contextual clues within the posted messages and then matched back.
0 = Male
1 = Female
2 = Unknown

V9. Role
0 = Unclassified
1 = Patient
2 = Spouse/Partner
3 = Child of patient
4 = Parent of patient
5 = Other family member of patient
6 = Medical professional
7 = Volunteer/Activist
8 = Friends
9 = Other

Social Support Variables (Variables 10 – 21)

Emotional Support Variables (V10 – V15)

Emotional support is defined as support interactions where emotional appeals are given from one person to another. These emotional appeals may include expressions of understanding, reassurance, sending "positive energy", compassion, and sympathy. In addition to overt expressions of emotional support, miscellaneous support materials such as poems, prayers, inspirational stories, and relations of personal experience for support purposes are considered to be instances of emotional support.

V10. Prayer / Spiritual Support

The prayer/spiritual support subtype is defined as emotional support interactions where offers to pray for someone, spiritual advice, quotations of scripture, or other spiritual matters are provided by one person.

Examples of Prayer / Spiritual Support may look something like:

- "You are in my prayers."
- "I'm sending you positive energy."
- "Matthew 3:10 says…"
- "Sometimes God calls us home."

To Code:
0 = No
1 = Yes

V11. Understanding Support

The understanding support subtype is defined as emotional support interactions where one person offers words of understanding or relates personal experiences to another in order to demonstrate that they identify with the support recipient. In order to qualify as understanding support, there needs to be some personal appeal from one person to another indicating that the support provider has an understanding of the recipient's situation.

Examples of Understanding Support may look something like:

- "I understand where you are coming from."
- "I experienced the same thing with my mother."
- "When my husband was diagnosed, I also felt the same thing"
- "I know exactly what you are going through... when I was diagnosed..."
- "When I first went on chemo, I felt even sicker as well."
- "I would have done the same thing"

To Code:
0 = No
1 = Yes

V12. Sympathy Support

The sympathy support subtype is defined as emotional support interactions where one person offers words sympathy to another.

Examples of Sympathy Support may look something like:

- "I am so sorry for your loss."
- "I am sorry that this has happened to you."
- "Words cannot describe the sadness I feel for you."

Note: Interactions where someone says "I'm sorry" for something non-support related will not be coded (i.e., "I'm sorry your pen ran out of ink").

To Code:
0 = No
1 = Yes

V13. Welcoming/Belonging Support

The welcoming/belonging support subtype is defined as emotional support interactions where one person offers words of welcome or belonging to new or established community members. These interactions typically appear when a new community member introduces him/herself to the community.

Examples of Welcoming Support may look something like:

- "Welcome to the community."
- "We are so glad to have you here."
- "You have found a home in us."
- "You are a member of this community"
- "You belong here with us"
- "You are one of us"

To Code:

0 = No
1 = Yes

V14. Encouragement Support

The encouragement support subtype is defined as emotional support interactions where one person offers words of encouragement another. This category also includes instances of jokes, anecdotes, inspirational stories or images, etc.

Examples of Encouragement Support may look something like:

- "Don't give up."
- "I support you in your decision."
- "You can get through this."
- "You are not alone."
- "Just take it one day at a time."
- "I'm glad to hear you are doing well."
- "It is wonderful that XXXX is doing well."
- Images or stories meant to make someone smile.
- Positive responses to support provisions, images, stories, etc.

To Code:

0 = No
1 = Yes

V15. Offers for Direct Contact

The Offers for Direct Contact support subtype is defined as an interaction where one person directly offers their services to another through various channels such as telephone, email, instant message, blog, etc.

Examples of Offers for Direct Contact may look something like:

- "Feel free to contact me at any time."
- "My phone number is XXX-XXXX, call me whenever you need me."
- "My email address is asdf@asdf.com, email me whenever you need someone to talk to."

To Code:

0 = No
1 = Yes

Informational Support Variables (V16 – V20)

Informational support is defined as any support interaction where informational aid is directly given from one person to another. Informational aid will be coded according to the different types of assistance.

DECISION RULE: AS V16 – V19 ARE SUBTYPES OF V20 (GENERAL INFORMATIONAL SUPPORT), ANY ONE SUPPORT INTERACTION THAT COULD BE CLASSIFIED AS BOTH INFORMATIONAL SUPPORT AND ONE OF THE SUBTYPES WILL BE CODED ACCORDING TO THE SUBTYPE.

V16. Mediated Resource Information (Informational Support Subtype)

Mediated resource information is defined as any information one person offers to another that is related to mediated resources such as books, websites, movies, TV shows, other online communities, chat rooms, etc. Any type of printed resource that is related to the topic at hand is considered to be a part of this category. Interactions that describe the content of a printed resource listed are still to be coded as printed resource information.

Examples of printed resource information may look like:

- "There is a great website on Condition X located at www….."
- "Check out community X, they have great pain management advice"
- "The book *XXXXXXX* written by John Smith has a lot of good information about…"
- "The Today show is having a spot on cancer tomorrow morning"

To Code:

0 = No
1 = Yes

V17. Live Assistance Resource Information (Informational Support Subtype)

Live assistance resource information is defined as any information one person offers to another that is related to live resources available offline regarding a particular disease / condition.

Examples of live assistance resource information may look like:

- "The National Diabetes Network offers free disease management seminars"
- "There is a support hotline offered through X that you can call for help"
- "Contact this number to find your local hospice provider XXX-XXX-XXXX"
- "There is a specialist in your area named Dr. Smith"

To Code:

0 = No
1 = Yes

V18. Disease / Symptom Information (Informational Support Subtype)

Disease and Symptom information is defined as any information one person offers to another that is related to characteristics of a disease or symptoms associated with a particular disease / condition.

Examples of disease / symptom information may look like:

- "Symptoms of Condition X include"
- "Dry mouth is a symptom association with Condition X"
- "HIV/AIDS kills XXXX number of people a year"
- "There are X number of different forms of MS"

NOTE: Personal accounts and opinions regarding experienced symptoms are not to be considered a part of this category. Only information that is seen as unbiased should be considered. Finally, interactions that include unreliable sources of information are not considered to be informational support.

To Code:

0 = No
1 = Yes

V19. Medication / Treatment Information (Informational Support Subtype)
Medication / Treatment information is defined as any information one person offers to another that is related to different medications, treatments, or therapies related to the disease/condition. This includes information regarding disease management.

Examples of medication / treatment information may look like:
- "There is a new type of treatment called X"
- "Medication X has been known to cause the symptoms you describe"
- "Have you heard about the new drug for your condition called X?"
- "Lipitor is a drug that is used to lower cholesterol"

NOTE: Personal accounts of what medications a person is currently taking are not to be considered a part of this category. Also, personal opinions about medications are not to be considered a part of this category. Finally, interactions that include unreliable sources of information are not considered to be informational support. Examples of what NOT to code may include:
- "I use Lipitor to lower cholesterol"
- "My doctor put me on insulin to help control my blood sugar"

To Code:
0 = No
1 = Yes

V20. General Cancer Informational Support
Informational support is defined as support interactions where unbiased information is given regarding anything that is on topic.

Examples of informational support may look something like:
- "There are several different types of wheelchairs, including X and Y"
- "Band-Aid produces a bandage that is waterproof"
- "There are gluten-free communion wafers commercially available"
- "X is a grocery store that caters to people with special dietary needs"
- "November is national breast cancer awareness month"
- "There will a conference on XXXXXX next October"

NOTE: Interactions that include unreliable sources of information are not considered to be informational support. For example:
- "I've heard that zinc is good for fighting colds"
- "I've been told that Nabisco makes a gluten free product"
- "I've always been told that carrots are good for your eyes"

To Code:
0 = No
1 = Yes

Instrumental Support (V21)

V21. Instrumental Support

This category is designed to code any support interaction that cannot be defined as either emotional support or informational support. This leaves room for the third type of support, instrumental support. Examples include offers of non-information related goods and services.

Examples of Instrumental support may look something like:

- "I'm sending you money for treatment"
- "I'm sending you X"

To Code:

0 = No
1 = Yes

Works Cited

Abbate Daga, G., Gramaglia, C., Piero, A., & Fassino, S. (2006) Eating disorders and the Internet: cure and curse. *Eating and Weight Disorders, 11*(2), e68 – 71.

Alao, A. O., Yolles, J. C., & Armenta, W. (1999). Cybersuicide: The Internet and suicide. *The American Journal of Psychiatry, 156*(11), 1836 – 1837.

Allen, S. F., & Stoltenberg, C. D. (1995). Psychological separation of older adolescents and young adults from their parents: An investigation of gender differences. *Journal of Consulting and Development, 73*(5), 542 – 546.

American Cancer Society. (2007). *Cancer facts and figures 2007.* Atlanta: American Cancer Society.

Antoucci, T. C., & Akiyama, H. (1987). An examination of sex differences in social support among older men and women. *Sex Roles, 17*(11/12), 737 – 749.

Argyle, M. (1992). Benefits produced by supportive social relationships. In H. O. F. Veiel & U. Baumann (Eds.), *The meaning and measurement of social support* (pp. 13 – 32). New York: Hemisphere Publishing Company.

Ashton, W. A., & Fuehrer, A. (1993). Effects of gender and gender role identification of participant and type of social support resource on support seeking. *Sex Roles, 28*(7/8), 461 – 476.

Barnett, G. A., & Hwang, J. M. (2006). The use of the Internet for health information and social support: A content analysis of online breast cancer discussion groups. In M. Murero & R. E. Rice (Eds.), *The Internet and health care: Theory, research, and practice* (pp. 233 – 253). Mahwah, NJ: Lawrence Erlbaum Associates.

Barrera, M. (2000). Social support research in community psychology. In J. Rappaport & E. Seidman (Eds.), *Handbook of community psychology* (pp. 215 – 245). New York: Kluwer Academic/Plenum.

Barrera, M., & Ainlay, S. L. (1983). The structure of social support: A conceptual and empirical analysis. *Journal of Community Psychology, 11*(2), 133 – 143.

Barrera, M., Jr., Glasgow, R. E., McKay, H. G., Boles, S. M., & Feil, E. G. (2002). Do Internet–based support interventions change perceptions of social support? An experimental trial of approaches for supporting diabetes self-management. *American Journal of Community Psychology, 30*(5), 637 – 654.

Belle, D. (1982). The stress of caring: Women as providers of social support. In L. Goldberger & S. Breznitz (Eds.), *Handbook of stress: Theoretical and clinical aspects* (pp. 496 – 505). New York: Free Press.

Belle, D. (1987). Gender differences in the social moderators of stress. In R. C. Barnett, L. Biener, & G. K. Baruch (Eds.), *Gender and stress* (pp. 257 – 277). New York: Free Press.

Berger, B. D., Lehrmann, J. A., Larson, G., Alverno, L., & Tsao, C. I. (2005). Nonpsychotic, nonparaphilic self–amputation and the Internet. *Comprehensive Psychiatry, 46*(5), 380 – 383.

Berkman, L. F. (1985). The relationship of social networks and social support to morbidity and mortality. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 241 – 262). Orlando, FL: Academic Press.

Berkman, L. F., & Syme, S. L. (1979). Social networks, host resistance, and mortality: A nine-year follow-up study of Alameda County residents. *American Journal of Epidemiology, 109*(2), 186 – 204.

Bernstam, E. V., Shelton, D. M., Walji, M., & Meric-Bernstam, F. (2005). Instruments to assess the quality of health information on the World Wide Web: What can our patients actually use? *International Journal of Medical Informatics, 74*(1), 13 – 19.

Blank, T. O., & Adams-Blodnieks, M. (2007). The who and the what of usage of two cancer online communities. *Computers in Human Behavior, 23*(3), 1249 – 1257.

Blazer, D. (1982). Social support and mortality in an elderly community population. *American Journal of Epidemiology, 115*(5), 684 – 694.

Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication, 11*(2), 123 – 151.

Bremner, J. D., Quinn, J., Quinn, W., & Veledar, E. (2006). Surfing the net for medical information about psychological trauma: An empirical study of the quality and accuracy of trauma-related websites. *Medical Informatics and the Internet in Medicine, 31*(3), 227 – 236.

Brissette, I., Cohen, S., & Seeman, T. (2000). Measuring social integration and social networks. In S. Cohen, L. Underwood, & B. H. Gottlieb (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 53 – 85). New York: Oxford University Press.

Burda, P. C., Jr., Vaux, A., & Schill, T. (1984). Social support resources: Variations in sex and sex-role. *Personality and Social Psychology Bulletin, 10*(1), 119 – 126.

Burke, R. J., & Weir, T. (1977). Marital helping relationships: The moderators between stress and well being. *Journal of Psychology, 95*, 121 – 130.

Burleson, B. R., Albrecht, T. L., Goldsmith, D. J., & Sarason, I. G. (1994). Introduction: The communication of social support. In B. R. Burleson, T. L. Albrecht, & I. G. Sarason (Eds.), *Communication of social support: Messages, interactions, relationships, and community* (pp. xi – xxx). Thousand Oaks, CA: Sage Publications.

Butler, L., & Foster, N. E. (2003). Back pain online: A cross-sectional survey of the quality of web-based information on low back pain. *Spine, 28*(4), 395 – 401.

Butler, R. J., III, Friel, D. F., Lang, R. D., Park, G., & Santello, S. A. (2000). Healthcare provider-sponsored virtual communities: The benefits of the electronic village. *Journal of Healthcare Information Management, 14*(1), 65 – 71.

Butler, T., Giordano, S., & Neren, S. (1985). Gender and sex-role attributions as predictors of utilization and natural support systems during personal stress events. *Sex Roles, 13*(9/10), 515 – 524.

Cassell, J. (1976). The contribution of the social environment to host resistance. *American Journal of Epidemiology, 104*(2), 107 – 123.

CHESS. (2006). CHESS: Comprehensive Health Enhancement Support System. Retrieved on March 28, 2007, from http://chess.chsra.wisc.edu/Chess/default.htm.

Christensen, K., & Levinson, D. (Eds.). (2003). *Encyclopedia of community: From the village to the virtual world* (Vols. 1 – 4). Thousand Oaks, CA: Sage Publications, Inc.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine, 38*(5), 300 – 314.

Cohen, S. (1992). Stress, social support, and disorder. In H. O. F. veiel & U. Baumann (Eds.), *The meaning and measurement of social support* (pp. 109 – 124). New York: Hemisphere Publishing Company.

Cohen, S., & McKay, G. (1984). Social support, stress and the buffering hypothesis: A theoretical analysis. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of psychology and health, Vol. IV: Social psychological aspects of health* (pp. 253 – 267). Hillsdale, NJ: Erlbaum.

Cohen, S., & Syme, S. L. (1985). Issues in the study and application of social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 3 – 22). Orlando, FL: Academic Press.

Commission of the European Communities, Brussels. (2002). eEurope 2002: Quality criteria for health–related Websites. *Journal of Medical Internet Research, 4*(3): e15.

Cramer, L. A., Riley, P. J., & Kiger, G. (1991). Support and antagonism in social networks: Effects of community and gender. *Journal of Social Behavior and Personality, 6*(4), 991 – 1005.

Croft, D., & Peterson, M. (2002). An evaluation of the quality and contents of asthma education on the World Wide Web. *Chest, 121*(4), 1301 – 1307.

Cudney, S. A., & Weinert, C. (2000). Computer-based support groups. Nursing in cyberspace. *Computers in Nursing, 18*(1), 35 – 43; quiz 44–36.

Cummings, J., Kiesler, S. B., & Sproull, L. (2002). Beyond hearing: Where real world and online support meet. *Group Dynamics: Theory Research, and Practice, 6*(1), 78 – 88.

Cutrona, C. E. (1990). Stress and social support: In search of optimal matching. *Journal of Social and Clinical Psychology, 9*(1), 3 – 14.

Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 319 – 366). New York: John Wiley.

Cutrona, C. E., & Suhr, J. A. (1992). Controllability of stressful events and satisfaction with spouse support behaviors. *Communication Research, 19*(2), 154 – 174.

Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist, 55*(2), 205 – 217.

Depner, C. E., & Ingersoll–Dayton, B. (1988). Supportive relationships in later life. *Psychology and Aging, 3*(4), 348 – 357.

Derlega, V. J., Barbee, A. P., & Winstead, B. A. (1994). Friendship, gender, and social support: Laboratory studies of supportive interactions. In B. R. Burleson, T. L. Albrecht, & I. G. Sarason (Eds.), *Communication of social support: Messages, interactions, relationships, and community* (pp. 136 – 151). Thousand Oaks, CA: Sage Publications.

Dobson, R. (1999). Internet sites may encourage suicide. *British Medical Journal, 319*(7206), 337.

Dunham, P. J., Hurshman, A., Litwin, E., Gusella, J., Ellsworth, C., & Dodd, P. W. (1998). Computer–mediated social support: Single young mothers as a model system. *American Journal of Community Psychology, 26*(2), 281 – 306.

Dunkel–Schetter, C., & Bennett, T. L. (1990). Differentiating the cognitive and behavioral aspects of social support. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 267 – 296). New York: Wiley.

Dunkel–Schetter, C., & Skokan, L. A. (1990). Determinants of social support provision in personal relationships. *Journal of Social and Personal Relationships, 7*(4), 437 – 450.

Durkheim, E. (1951). *Suicide: A study in sociology*. London: The Free Press.

Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA: A Cancer Journal for Clinicians, 53*(6), 356 – 371.

Eysenbach, G., & Kohler, C. (2004). Health–related searches on the Internet. *Journal of the American Medical Association, 291*(24), 2946.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *British Medical Journal, 328*(7449), 1166.

Eysenbach, G., Powell, J., Kuss, O., & Sa, E. (2002). Empirical studies assessing the quality of health information for consumers on the World Wide Web: A systematic review. *Journal of the American Medical Association, 287*(20), 2691 – 2700.

Eysenbach, G., & Till, J. E. (2001). Ethical issues in qualitative research on Internet communities. *British Medical Journal, 323*(7321), 1103 – 1105.

Fischer, C. S. (1982). *To dwell among friends: Personal networks in town and city*. Chicago: University of Chicago Press.

Flicker, S., Haans, D., & Skinner, H. (2004). Ethical dilemmas in research on Internet communities. *Qualitative Health Research, 14*(1), 124 – 134.

Fogel, J., Albert, S. M., Schnabel, F., Ditkoff, B. A., & Neugut, A. I. (2002). Internet use and social support in women with breast cancer. *Health Psychology, 21*(4), 398 – 404.

Fox, N., Ward, K., & O'Rourke, A. (2005). Pro-anorexia, weight–loss drugs and the Internet: An 'anti-recovery' explanatory model of anorexia. *Sociology of Health & Illness, 27*(7), 944 – 971.

Fox, S. (2006). *Online health search 2006*. Retrieved on March 8, 2007, from http://207.21.232.103/pdfs/PIP_Online_Health_2006.pdf.

Fox, S., & Rainie, L. (2000). The online healthcare revolution: How the web helps Americans take care of themselves. Retrieved March 30, 2007, from http://www.pewinternet.org/pdfs/PIP_Health_Report.pdf.

Gallant, M. P. (2003). The influence of social support on chronic illness self–management: A review and directions for research. *Health Education & Behavior, 30*(2), 170 – 195.

Glueckauf, R. L., Ketterson, T. U., Loomis, J. S., & Dages, P. (2004). Online support and education for dementia caregivers: Overview, utilization, and initial program evaluation. *Telemedicine Journal and E-Health, 10*(2), 223 – 232.

Goldsmith, D. J. (2004). *Communicating social support*. New York: Cambridge University Press.

Google. (2007). About Google scholar. Retrieved on March 17, 2007, from http://scholar.google.com/intl/en/scholar/about.html.

Gottlieb, B. H. (1998). Support groups. In H. S. Friedman (Ed.), *Encyclopedia of mental health*. San Diego, CA: Academic Press.

Grande, G. E., Myers, L. B., & Sutton, S. R. (2006). How do patients who participate in cancer support groups differ from those who do not? *Psycho-oncology, 15*(4), 321 – 334.

Gray, N. J., Klein, J. D., Noyce, P. R., Sesselberg, T. S., & Cantrill, J. A. (2004). Health information seeking behaviour in adolescence: The place of the Internet. *Social Science and Medicine, 60*(7), 1467 – 1478.

Greene, D. L., Appel, A. J., Reinert, S. E., & Palumbo, M. A. (2005). Lumbar disc herniation: Evaluation of information on the Internet. *Spine, 30*(7), 826 – 829.

Griffith, J. (1985). Social support providers: Who are they? Where are they met? And the relationship of network characteristics to psychological distress. *Basic and Applied Social Psychology, 6*(1), 41 – 60.

Griffiths, K. M., & Christensen, H. (2005). Website quality indicators for consumers. *Journal of Medical Internet Research, 7*(5):e55.

Griffiths, K. M., Tang, T. T., Hawking, D., & Christensen, H. (2005). Automated assessment of the quality of depression websites. *Journal of Medical Internet Research, 7*(5):e59.

Hamman, R. B. (2001). Computer networks linking network communities. In C. Werry & M. Mowbray (Eds.), *Online communities: Commerce, community action, and the virtual university* (pp. 71 – 95). Upper Saddle River, NJ: Prentice–Hall.

Hanif, F., Sivaprakasam, R., Butler, A., Huguet, E., Pettigrew, G. J., Michael, E. D., et al. (2006). Information about liver transplantation on the World Wide Web. *Medical Informatics and the Internet in Medicine, 31*(3), 153 – 160.

Hargrave, D. R., Hargrave, U. A., & Bouffet, E. (2006). Quality of health information on the Internet in pediatric neuro–oncology. *Neuro–oncololgy, 8*(2), 175 – 182.

Helgeson, V. S. (2003). Social support and quality of life. *Quality of Life Research, 12*(Supplement 1), 25 – 31.

Helgeson, V. S., & Gottlieb, B. H. (2000). Support groups. In S. Cohen, L. Underwood, & B. H. Gottlieb (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 221 – 245). New York: Oxford University Press.

Hesse, B. W., Nelson, D. E., Kreps, G. L., Croyle, R. T., Arora, N. K., Rimer, B. K., et al. (2005). Trust and sources of health information: The impact of the Internet and its implications for health care providers: Findings from the first Health Information National Trends Survey. *Archives of Internal Medicine, 165*(22), 2618 – 2624.

Hill, W. G., & Weinert, C. (2004). An evaluation of an online intervention to provide social support and health education. *Computers, Informatics, Nursing: CIN, 22*(5), 282 – 288.

Hillery, G. A., Jr., (1955). Definitions of community: Areas of agreement. *Rural Sociology, 20*(2), 111 – 123.

House, J. S. (1981). *Work stress and social support*. Reading, MA: Addison–Wesley.

House, J. S., & Kahn, R. L. (1985). Measures and concepts of social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 83 – 108). Orlando, FL: Academic Press.

House, J. S., Robbins, C., & Metzner, H. (1982). The association of social relationships and activities with mortality: Prospective evidence from the Tecumseh community health study. *American Journal of Epidemiology, 116*(1), 123 – 140.

Houston, T. K., Cooper, L. A., & Ford, D. E. (2002). Internet support groups for depression: A 1-year prospective cohort study. *The American Journal of Psychiatry, 159*(12), 2062 – 2068.

Hupcey, J. E. (1998). Clarifying the social support theory–research linkage. *Journal of Advanced Nursing, 27*(6), 1231 – 1241.

Ilic, D., Risbridger, G., & Green, S. (2004). Searching the Internet for information on prostate cancer screening: An assessment of quality. *Urology, 64*(1), 112 – 116.

Impicciatore, P., Pandolfini, C., Casella, N., Bonati, M. (1997). Reliability of health information for the public on the World Wide Web: Systematic survey of advice on managing fever in children at home. *British Medical Journal, 314*(7098), 1875 – 1879.

Jacobson, D. E. (1986). Types and timing of social support. *Journal of Health and Social Behavior, 27*(3), 250 – 264.

Junghans, T. B., Sevin, I. F., Ionin, B., & Seifried, H. (2004). Cancer information resources: Digital and online sources. *Toxicology, 198*(1-3), 177 – 193.

Kaid, L. L., & Wadsworth, A. J. (1989). Content analysis. In P. Emmert & L. L. Barker (Eds.), *Measurement of communication behavior* (pp. 197 – 217) New York: Longman.

Kendler, K. S., Myers, J., & Prescott, C. A. (2005). Sex differences in the relationship between social support and risk for major depression: A longitudinal study of opposite-sex twin pairs. *American Journal of Psychiatry, 162*(2), 250 – 256.

Kessler, R. C., McLeod, J. D., & Wethington, E. (1985). The costs of caring: A perspective on the relationship between sex and psychological distress. In I. G. Sarason & B. R. Sarason (Eds.), *Social support: Theory, research, and applications*. The Hague, Netherlands: Martinus Nijhoff.

Klemm, P., Hurst, M., Dearholt, S. L., & Trone, S. R. (1999). Gender differences on Internet cancer support groups. *Computers in Nursing, 17*(2), 65 – 72.

Klemm, P., Reppert, K., & Visich, L. (1998). A nontraditional cancer support group: The Internet. *Computers, Informatics, Nursing: CIN, 16*(1), 31 – 36.

Klemm, P., & Wheeler, E. (2005). Cancer caregivers online: Hope, emotional roller coaster, and physical/emotional/psychological responses. *Computers, Informatics, Nursing: CIN, 23*(1), 38 – 45.

Krizek, C., Roberts, C., Ragan, R., Ferrara, J. J., & Lord, B. (1999). Gender and cancer support group participation. *Cancer Practice, 7*(2), 86 – 92.

Kunst, H., Groot, D., Latthe, P. M., Latthe, M., & Khan, K. S. (2002). Accuracy of information on apparently credible websites: Survey of five common health topics. *British Medical Journal, 324*(7337), 581 – 582.

LaCoursiere, S. P., Knobf, M. T., & McCorkle, R. (2005). Cancer patients' self-reported attitudes about the Internet. *Journal of Medical Internet Research, 7*(3):e22.

Lamberg, L. (2003). Online empathy for mood disorders: Patients turn to Internet support groups. *Journal of the American Medical Association, 289*(23), 3073 – 3077.

Lasker, J. N., Sogolow, E. D., & Sharim, R. R. (2005). The role of an online community for people with a rare disease: Content analysis of messages posted on a primary biliary cirrhosis mailinglist. *Journal of Medical Internet Research, 7*(1):e10.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing Company.

Lester, J., Prady, S., Finegan, Y., & Hoch, D. (2004). Learning from e–patients at Massachusetts general hospital. *British Medical Journal, 328*(7449), 1188 – 1190.

Lieberman, M. A., Golant, M., Giese–Davis, J., Winzlenberg, A., Benjamin, H., Humphreys, K., et al. (2003). Electronic support groups for breast carcinoma: A clinical trial of effectiveness. *Cancer, 97*(4), 920 – 925.

Liu, Y., & Liu, M. (2006). Osteosarcoma: Evaluation of information on the Internet. *Telemedicine Journal and e–Health, 12*(5), 542 – 545.

L-Soft. (2005). L-Soft Interviews Gilles Frydman, President of ACOR. Retrieved on March 30, 2007, from http://www.lsoft.com/news/qa-issue1-2005-us.asp.

Lombard, M., Snyder-Duch, J., & Bracken, C. C. (2002). Content analysis in mass communication: Assessment and reporting of intercoder reliability. *Human Communication Research, 28*(4), 587 – 604.

Luttik, M. L., Jaarsma, T., Moser, D., Sanderman, R., & Van Veldhuisen, D. J. (2005). The importance and impact of social support on outcomes in patients with heart failure: An overview of the literature. *Journal of Cardiovascular Nursing, 20*(3), 162 – 169.

Madara, E. J. (1997). The mutual–aid self–help online revolution. *Social Policy, 27*(3), 20 – 26.

Madden, M. (2006). Internet penetration and impact. Retrieved on March 17, 2007, from http://www.pewinternet.org/pdfs/PIP_Internet_Impact.pdf.

Maloney, S., Ilic, D., & Green, S. (2005). Accessibility, nature and quality of health information on the Internet: A survey on osteoarthritis. *Rheumatology, 44*(3), 382 – 385.

Mathur, S., Shanti, N., Brkaric, M., Sood, V., Kubeck, J., Paulino, C., et al. (2005). Surfing for scoliosis: The quality of information available on the Internet. *Spine, 30*(23), 2695 – 2700.

Matthews, S. C., Camacho, A., Mills, P. J., & Dimsdale, J. E. (2003). The Internet for medical information about cancer: Help or hindrance? *Psychosomatics, 44*(2), 100 – 103.

Mayer, M. A., Karkaletsis, V., Archer, P., Ruiz, P., Stamatakis, K., & Leis, A. (2006). Quality labelling of medical web content. *Health Informatics Journal, 12*(1), 81 – 87.

Mendelson, C. (2003). Gentle hugs: Internet listservs as sources of support for women with lupus. *Advances in Nursing Science, 26*(4), 299 – 306.

Meric, F., Bernstam, E. V., Mirza, N. Q., Hunt, K. K., Ames, F. C., Ross, M. I., et al. (2002). Breast cancer on the World Wide Web: Cross sectional survey of quality of information and popularity of Websites. *British Medical Journal, 324*(7337), 577 – 581.

Monnier, J., Laken, M., & Carter, C. L. (2002). Patient and caregiver interest in Internet–based cancer services. *Cancer Practice, 10*(6), 305 – 310.

Moos, R. H., Moos, B. S., & Timko, C. (2006). Gender, treatment and self–help in remission from alcohol use disorders. *Clinical Medicine & Research, 4*(3), 163 – 174.

Mulveen, R., & Hepworth, J. (2006). An interpretative phenomenological analysis of participation in a pro-anorexia Internet site and its relationship with disordered eating. *Journal of Health Psychology, 11*(2), 283 – 296.

Neuendorf, K. A. (2002). *The content analysis guidebook.* Thousand Oaks, CA: Sage Publications.

Nip, J. (2004). The relationship between online and offline communities: The case of the queer sisters. *Media, Culture, & Society, 26*(3), 409 – 428.

Nonnecke, B., & Preece, J. (2003). Silent participants: Getting to know lurkers better. In C. Lueg & D. Fisher (Eds.), *From usenet to cowebs: Interacting with social information spaces* (pp. 110 – 132). London: Springer.

Norris, M. L., Boydell, K. M., Pinhas, L. & Katzman, D. K. (2006). Ana and the Internet: A review of pro-anorexia websites. *International Journal of Eating Disorders, 39*(6), 443 – 447.

O'Brien, J. (1999). Writing in the body: Gender (re)production in online interaction. In M. Smith & P. Kollok (Eds.), *Communities in cyberspace* (pp. 76 – 104). New York: Routledge.

Owen, J. E., Klapow, J. C., Roth, D. L., Nabell, L., & Tucker, D. C. (2004). Improving the effectiveness of adjuvant psychological treatment for women with breast cancer: The feasibility of providing online support. *Psycho-oncology, 13*(4), 281–292.

Owen, J. E., Klapow, J. C., Roth, D. L., & Tucker, D. C. (2004). Use of the Internet for information and support: Disclosure among persons with breast and prostate cancer. *Journal of Behavioral Medicine, 27*(5), 491 – 505.

Pearlin, L. I. (1985). Social structure and processes of social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 43 – 60). Orlando, FL: Academic Press.

Perron, B. (2002). Online support for caregivers of people with a mental illness. *Psychiatric Rehabilitation Journal, 26*(1), 70 – 77.

Pierce, L. L., Steiner, V., & Govoni, A. L. (2002). In-home online support for caregivers of survivors of stroke: A feasibility study. *Computers, Informatics, Nursing: CIN, 20*(4), 157 – 164.

Powell, J., McCarthy, N., & Eysenbach, G. (2003). Cross–sectional survey of users of Internet depression communities. *BMC Psychiatry, 3*(1), 19.

Prior, T. I. (2004). Suicide methods from the Internet. *American Journal of Psychiatry, 161*(8), 1500 – 1501.

Preece, J. (2000). *Online communities, designing usability and supporting sociability.* Chichester, England: John Wiley & Sons, LTD.

Preece, J., Nonnecke, B., & Andrews, D. (2004). The top five reasons for lurking: Improving community experiences for everyone. *Computers in Human Behavior, 20*(2), 201 – 223.

Pubmed. (2007). Pubmed. Retrieved on March 17, 2007, from http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?DB=pubmed.

Rainie, L., & Horrigan, J. (2005). Trends 2005. Retrieved March 30, 2007, from http://pewresearch.org/assets/files/trends2005.pdf.

Rajagopal, S. (2004). Suicide pacts and the Internet. *British Medical Journal, 329*(7478), 1298 – 1299.

Ramos, J. D., Rai–Chaudhuri, A., & Neill, R. W. (2004). International online discussion lists on chronic myelogenous leukaemia. *British Medical Journal, 328*(7449), 1177 – 1178.

Rheingold, H. (1993). *The virtual community: Homesteading on the electronic frontier.* Reading, MA: Addison-Wesley.

Rhodes, S. D., Bowie, D. A., & Hergenrather, K. C. (2003). Collecting behavioural data using the World–Wide Web: Considerations for researchers. *Journal of Epidemiology and Community Health, 57*(1), 68 – 73.

Riffe, D., Lacy, S., & Fico, F. G. (2005). *Analyzing media messages: Using quantitative content analysis in research.* Mahwah, NJ: Lawrence Erlbaum Associates.

Riley, D., & Eckenrode, J. (1986). Social ties: Subgroup differences in costs and benefits. *Journal of Personality and Social Psychology, 51*(4), 770 – 778.

Robinson, N. S. (1995). Evaluating the nature of perceived support and its relation to perceived self–worth in adolescents. *Journal of Research on Adolescence, 5*(2), 253 – 280.

Rosenthal, K. R., Gesten, E. L., & Shiffman, S. (1986). Gender and sex role differences in the perception of social support. *Sex Roles, 14*(9/10), 481 – 499.

Sabel, M. S., Strecher, V. J., Schwartz, J. L., Wang, T. S., Karimipour, D. J., Orringer, J. S., et al. (2005). Patterns of Internet use and impact on patients with melanoma. *Journal of the American Academy of Dermatology, 52*(5), 779 – 785.

Santoro, E. (2003). Internet and information on breast cancer: An overview. *Breast, 12*(6), 424 – 431.

Sarason, B. R., Pierce, G. R., & Sarason, I. G. (1990). Social support: The sense of acceptance and the role of relationships. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 97 – 128). New York: John Wiley & Sons.

Sarason, B. R., Sarason, I. G., & Pierce, G. R. (1990). Traditional views of social support and their impact on assessment. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 9 – 25). New York: John Wiley & Sons.

Sarason, I. G., Sarason, B. R., & Pierce, G. R. (1994). Relationship–specific social support: Toward a model for the analysis of supportive interactions. In B. R. Burleson, T. L. Albrecht, & I. G. Sarason (Eds.), *Communication of social support: Messages, interactions, relationships, and community* (pp. 91 – 112). Thousand Oaks, CA: Sage Publications.

Seale, C., Ziebland, S., & Charteris–Black, J. (2006). Gender, cancer experience and Internet use: A comparative keyword analysis of interview and online cancer support groups. *Social Science & Medicine, 62*(10), 2577 – 2590.

Selman, T. J., Prakash, T., & Khan, K. S. (2006). Quality of health information for cervical cancer treatment on the Internet. *BMC Womens Health, 6*:9.

Soliman, A. M. (1993). Choice of helpers, types of problem and sex of helpers of college students. *International Journal for the Advancement of Counseling, 16*(2), 67 – 79.

Sullivan, C. F. (2003). Gendered cybersupport. A thematic analysis of two online cancer support groups. *Journal of Health Psychology, 8*(1), 83 – 103.

Sutherland, L. A., Wildemuth, B., Campbell, M. K., & Haines, P. S. (2005). Unraveling the web: An evaluation of the content quality, usability, and readability of nutrition web sites. *Journal of Nutrition Education and Behavior, 37*(6), 300 – 305.

Thoits, P. A. (1992). Social support functions and network structures: A supplemental view. In H. O. F. veiel & U. Baumann (Eds.), *The meaning and measurement of social support* (pp. 57 – 62). New York: Hemisphere Publishing Corporation.

Thomas, W., & Znaniecki, F. (1920). *The polish peasant in Europe and America.* New York: Knopf.

Tichon, J. G., & Shapiro, M. (2003). The process of sharing social support in cyberspace. *Cyberpsychology & Behavior, 6*(2), 161 – 170.

Tichon, J., & Yellowlees, P. (2003). Internet social support for children and adolescents. *Journal of Telemedicine and Telecare, 9*(4), 238 – 240.

Tierney, S. (2006). The dangers and draw of online communication: Pro-anorexia websites and their implications for users, practitioners, and researchers. *Eating Disorders, 14*(3), 181 – 190.

Till, J. E. (2003). Evaluation of support groups for women with breast cancer: Importance of the navigator role. *Health and Quality of Life Outcomes, 1*(1), 16.

Tiller, G., Rea, S., Silla, R., & Wood, F. (2006). Burns first aid information on the Internet. *Burns, 32*(7), 897 – 901.

Trobst, K. K., Collins, R. L., & Embree, J. M. (1994). The role of emotion in social support provision: Gender, empathy and expressions of distress. *Journal of Social and Personal Relationships, 11*(1), 45 – 62.

Turner, G., & Shepherd, J. (1999). A method in search of a theory: Peer education and health promotion. *Health Education Research, 14*(2), 235 – 247.

Turner, H. A. (1994). Gender and social support: Taking the bad with the good? *Sex Roles, 30*(7/8), 521 – 541.

Uchino, B. N. (2004). *Social support and physical health: Understanding the health consequences of relationships.* New Haven, CT: Yale University Press.

Vaux, A. (1985). Variations in social support associated with gender, ethnicity and age. *Journal of Social Issues, 41*(1), 89 – 110.

Vaux, A. (1988). *Social support: Theory, research, and intervention.* New York: Praeger.

Verheijden, M. W., Bakx, J. C., van Weel, C., Koelen, M. A., & van Staveren, W. A. (2005). Role of social support in lifestyle–focused weight management interventions. *European Journal of Clinical Nutrition, 59*(Supplement 1), S179 – S186.

Weinberg, N., Schmale, J., Uken, J., & Wessel, K. (1996). Online help: Cancer patients participate in a computer–mediated support group. *Health & Social Work, 21*(1), 24 – 29.

Weinrich, J. D. (1997). Strange bedfellows: Homosexuality, gay liberation, and the Internet. *Journal of Sex Education and Therapy, 22*(1), 58 – 66.

Wellman, B., & Gulia, M. (1999). Virtual communities as communities: Net surfers don't ride alone. In M. Smith & P. Kollok (Eds.), *Communities in cyberspace* (pp. 167 – 194). New York: Routledge.

Wethington, E., & Kessler, R. D. (1986). Perceived support, received support, and adjustment to stressful life events. *Journal of Health and Social Behavior, 27*(1), 78 – 89.

White, M., & Dorman, S. M. (2000). Online support for caregivers: Analysis of an Internet Alzheimer mailgroup. *Computers in Nursing, 18*(4), 168 – 179.

White, M., & Dorman, S. M. (2001). Receiving social support online: Implications for health education. *Health Education Research, 16*(6), 693 – 707.

Whitlock, J. L., Powers, J. L., & Eckenrode, J. (2006). The virtual cutting edge: The Internet and adolescent self-injury. *Developmental Psychology, 42*(3), 407 – 417.

Wilcox, B., & Vernberg, B. (1985). Conceptual and theoretical dilemmas facing social support research. In I. G. Sarason & B. R. Sarason (Eds.), *Social support: Theory, research and applications* (pp. 3 – 20). The Hague, Netherlands: Martinus Nijhoff.

Winkelman, W. J., & Choo, C. W. (2003). Provider-sponsored virtual communities for chronic patients: Improving health outcomes through organizational patient–centered knowledge management. *Health Expectations, 6*(4), 352 – 358.

Winzelberg, A. J., Classen, C., Alpers, G. W., Roberts, H., Koopman, C., Adams, R. E., et al. (2003). Evaluation of an Internet support group for women with primary breast cancer. *Cancer, 97*(5), 1164 – 1173.

Woods, V. (2005). Work–related musculoskeletal health and social support. *Occupational Medicine, 55*(3), 177 – 189.

Yahoo. (2005). The history of Yahoo! – How it all started. Retrieved on March 30, 2007, from http://docs.yahoo.com/info/misc/history.html.

Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S., & Rozmovits, L. (2004). How the Internet affects patients' experience of cancer: A qualitative study. *British Medical Journal, 328*(7439), 564.